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'Contention' in multiple myeloma: the impact on life and supportive care needs.

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Submitted to City University, London, for the degree of Doctor of Philosophy

School of Community and Health Sciences
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List of Contents

List of tables 5
List of figures 5
Acknowledgements 7
Declaration 8
Abstract 9
Glossary of Terms 10
Chapter 1. Background to the study 14
1.1 Introduction 14
1.2 The concept of contention 14
1.3 The researcher's perspective 15
1.4 Dual role of nurse and researcher 15
1.5 Attending the chemotherapy day care unit 16
1.6 What is multiple myeloma? 18
1.6.1 Incidence 18
1.6.2 Classifications 19
1.6.3 Clinical features 21
1.6.4 Treatment 21
1.6.5 The physiological impact of treatment 22
1.6.6 The psychological impact of treatment 23
1.7 Assumptions and context of care delivery 23
1.8 Justification for the study 25
1.9 The policy context 25
1.10 Aims and objectives 27
1.11 Summary 27
Chapter 2. Literature review 29
2.1 Introduction 29
2.2 The 2008 literature review 29
2.2.1 Returning to the literature 29
2.2.2 Scope of literature search 29
2.2.3 Approach to qualitative meta-synthesis 30
2.3 Communication 31
2.3.1 Doctors breaking bad news 32
2.3.2 Patients receiving bad news 33
2.3.3 Responses to bad news 35
2.3.4 Language and interpretations 37
2.3.5 Interactions during treatment 39
2.3.6 Talking to children about cancer 41
2.4 Impact on life 42
2.4.1 Disrupted life 42
2.4.2 Quality of life 45
2.4.3 Delay of diagnosis 46
2.4.4 Experiencing recurrence 48
2.4.5 Impact on family 51
2.4.6 Life following transplant 53
2.5 Supportive care needs 55
2.5.1 Support barriers 55
2.5.2 Differences in gender 58
2.5.3 Making choices 59

2.5.4 Support categories 61
2.5.5 Financial support 63
2.5.6 Prioritisation of support 65
2.6 Summary 67
Chapter 3. Research methodology 68
3.1 Introduction 68
3.2 The study site 69
3.3 Population and sample 69
3.3.1 Purposive sampling 70
3.3.2 Theoretical sampling 72
3.4 Gaining access 72
3.5 Research design 74
3.6 Data Collection 75
3.7 Data analysis 78
3.7.1 Heading in many directions 79
3.7.2 Writing 'memos' 80
3.7.3 Returning transcripts for clarification 80
3.7.4 Amendments 81
3.7.5 The working example 81
3.7.6 Identifying the core category 85
3.7.7 Validation 85
3.8 Trustworthiness of the study 86
3.9 Methodological issues 88
3.9.1 Emergence verses forcing debate 88
3.9.2 Insider/practitioner researcher 89
3.9.3 Specific issues 92
3.10 Managing the project 94
3.11 Managing the data 95
3.12 Managing the time 97
3.13 Completed data collection 97
3.14 Categories emerged from the data 98
3.15 Personal reflections on the process 99
3.16 Summary 100
Chapter 4. Findings 101
4.1 Introduction 101
4.2 The participants 102
4.2.1 Patient and family profile memos 104
4.3 Ways of Communication 118
4.3.1 Introduction 118
4.4 Communicating with the doctor 119
4.4.1 The context 119
4.4.2 The analytical story line (Table 3) 120
4.5 Communicating bad news 121
4.5.1 The context 121
4.5.2 The analytical story line (Table 4) 123
4.6 Using complex terminology 125
4.6.1 The context 125
4.6.2 The analytical story line (Table 5) 125
4.7 Communicating with children 127
4.7.1 The context 127

4.7.2 The analytical story line (Table 6) 129
4.8 Hidden disclosure 130
4.8.1 The context 130
4.8.2 The analytical story line (Table 7) 132
4.9 Summary 133
4.10 Nature of the disease 134
4.10.1 Introduction 134
4.11 Delay in diagnosis 134
4.11.1 The context 134
4.11.2 The analytical story line (Table 8) 136
4.12 Living with uncertainty 137
4.12.1 The context 137
4.12.2 The analytical story line (Table 9) 139
4.13 Perception of the disease 140
4.13.1 The context 140
4.13.2 The analytical story line (Table 10) 143
4.14 From novice to expert patient 144
4.14.1 The context 144
4.14.2 The analytical story line (Table 11) 146
4.15 Summary 148
4.16 Impact on life 148
4.16.1 Introduction 148
4.17 Disrupted life 149
4.17.1 The context 149
4.17.2 The analytical story line (Table 12) 150
4.18 Physical impact of disease 151
4.18.1 The context 151
4.18.2 The analytical story line (Table 13) 153
4.19 Emotional impact of treatment 154
4.19.1 The context 154
4.19.2 The analytical story line (Table 14) 156
4.20 The physical impact of treatment 158
4.20.1 The context 158
4.20.2 The analytical story line (Table 15) 160
4.21 Impact on sexual relationships 161
4.21.1 The context 161
4.21.2 The analytical story line (Table 16) 162
4.22 Impact on family life 164
4.22.1 The context 164
4.22.2 The analytical story line (Table 17) 166
4.23 Summary 167
4.24 Supportive care needs 168
4.24.1 Introduction 168
4.25 Invisible struggle 169
4.25.1 The context 169
4.25.2 The analytical story line (Table 19) 170
4.26 Impact of policy 172
4.26.1 The context 172
4.26.2 The analytical story line (Table 20) 173
4.27 Decision making 174

4.27.1 The context 174
4.27.2 The analytical story line (Table 21) 176
4.28 Summary 178
Chapter 5. Discussion 181
5.1 Introduction 181
5.2 Metaphorical sense of meaning 182
5.3 Concept analysis 184
5.3.1 Introduction 184
5.3.2 Uses of the concept *Contention* 186
5.3.2.1 Dictionary definitions 188
5.3.3 Defining attributes 190
5.3.4 Constructing cases 191
5.3.4.1 A model case 191
5.3.4.2 A borderline case 192
5.3.4.3 A related case 193
5.3.4.4 A contrary case 194
5.3.4.5 An invented case 195
5.3.4.6 An illegitimate case 196
5.3.5 Identifying antecedents and consequences 196
5.3.6 Defining empirical referents 199
5.3.7 Defining the concept 200
5.3.8 Concluding remarks 201
5.4 Contention in communication 201
5.4.1 Delay 202
5.4.2 Bad news 206
5.4.3 Emotional labour 208
5.4.4 Complex language 209
5.4.5 Talking to children 210
5.4.6 Hidden disclosure 211
5.4.7 Sustaining realistic hope 211
5.5 Contention in nature of disease 212
5.5.1 Becoming knowledgeable 213
5.5.2 How others perceive us 214
5.6 Contention in impact on life 215
5.6.1 Impact of treatment 216
5.6.2 Impact on sexual relationships 218
5.6.3 Impact on family 218
5.7 Contention in supportive care needs 220
5.7.1 Invisible struggle 221
5.7.2 Impact of policy 223
5.7.3 Decision-making 224
5.8 Applicability of Contention in relation to other chronic illnesses 225
5.9 Limitations 227
5.10 Towards a model of supportive care 229
5.11 Summary and the emerging theory 231
Chapter 6 Conclusion 232
6.1 Introduction 232
6.2 Findings and their significance 232
6.2.1 Contention 232
6.2.2 The fundamental issues 233

6.3 Recommendations for practice **236**
6.4 Recommendations for education **237**
6.5 Recommendations for research **238**
6.6 Overall Contribution **240**
6.7 Dissemination of results **240**
6.8 Concluding remarks **240**

List of references **242**

List of tables

Table 1 Patients and family members 103
Table 2 Healthcare professionals 103
Table 3 Communicating with the doctor 121
Table 4 Communicating bad news 124
Table 5 Using complex terminology 127
Table 6 Communicating with children 130
Table 7 Hidden disclosure 133
Table 8 Delay in diagnosis 137
Table 9 Living with uncertainty 140
Table 10 Perceptions of the disease 144
Table 11 From novice to expert patient 147
Table 12 Disrupted life 151
Table 13 Physical impact of disease 154
Table 14 Emotional impact of treatment 157
Table 15 Physical impact of treatment 161
Table 16 Impact on sexual relationships 163
Table 17 Impact on family life 167
Table 18 Strategies and supportive care services (NICE 2004) 168
Table 19 Invisible struggle 172
Table 20 The impact of policy 174
Table 21 Decision-making 177
Table 22 Use of 'struggle', 'battle' and 'fight' in the data 184
Table 23 Framework for concept analysis 185
Table 24 Attributes derived from data analysis and literature 190
Table 25 Empirical referents of *Contention* 200

List of figures

Figure 1 Classifications of multiple myeloma 20
Figure 2 An outline of the evolving grounded theory research process 68
Figure 3 Completed data collection 97
Figure 4 Evolving category group model 99
Figure 5 Core category Contention, main categories and subcategories 101
Figure 6 Diagrammatic representation of the core category *Contention*. 179
Figure 7 Antecedents, defining attributes and consequences of *Contention* .. 198
Figure 8 Model of supportive care 230

List of appendices

Appendix 1 Chair-side nursing – The impetus for the study 257
Appendix 2 Publications 262
Appendix 3 Literature review (2004) 263
Appendix 4 Qualitative synthesis grid 264
Appendix 5 Synthesis interpretations 265
Appendix 6 Ethic committee approval 266
Appendix 7 Participant information sheet and consent 267
Appendix 8 Letter to patient (example) 270
Appendix 9 Integrated conceptual hypotheses 271
Appendix 10 Original interview schedule 274
Appendix 11 Topic guide 276
Appendix 12 Specific questions (analysis driven) 277
Appendix 13 Demographic data 278
Appendix 14 The emerging theory of *Contention* in multiple myeloma 279
Appendix 15 Validation narratives (examples) 282
Appendix 16 Project administration file 287
Appendix 17 Time plan 288
Appendix 18 Interview record 289
Appendix 19 Family self-assessment and referral plan 290

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Declaration

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Abstract

This grounded theory research explores patients' experiences and the supportive care implications of living with the incurable and progressive bone marrow cancer multiple myeloma. Patients (n=17), family members (n=11) and healthcare professionals (n=12) participated in the research. A total of 46 semi-structured and recorded interviews were undertaken and transcribed verbatim (three couples were interviewed twice n=6). Some participants were interviewed individually while others were interviewed as a couple or small family group. The methodology employed aimed to generate theory in an area of limited qualitative exploration and findings were determined through the procedures of theoretical sampling and constant comparative analysis. '*Contention'* was the core category that emerged in the form of 'struggle' with close affiliation to other prominent interrelating concepts such as 'battle' or 'fight', 'disruption' and 'disharmony'. The findings are described within four categories of '*Ways of communication', 'Nature of the disease', 'Impact on life' and 'Supportive care needs'.*

This research provides insight of individuals' life experiences living with a complex haematological malignancy that is poorly understood. Implications for practice relate to development of collaborative approaches to healthcare and the identification of supportive care needs. This work contributes increased awareness and understanding of multiple myeloma and the impact that the disease has on the individual and on family life. It also highlights the value of effective communication and collaboration between patients, families and healthcare professionals to identify supportive care needs at specific times along the illness trajectory and inform service provision and the development of effective care pathways. Indications for further research are included. A Family Self-Assessment Referral Plan and Model of Supportive Care, based on the research findings, are currently being developed in collaboration with patients, families, professionals and Myeloma UK.

Glossary of Terms

Allogeneic Stem cell transplant
Also called an Allograft. A transplant using stem cells collected from a matched healthy donor, usually a sister or brother. The risks associated with the procedure increase with age.

Alzheimer's disease
A progressive neurodegenerative disease characterised by loss of function and death of nerve cells in several areas of the brain leading to loss of cognitive function such as memory and language.

Apheresis
A procedure in which stem cells are collected from the blood using a machine which separates them out, returning the remainder of the blood components to the donor.

Bence-Jones proteins
A characteristic protein found in the urine of some patients with multiple myeloma.

Bone marrow biopsy and aspiration
A procedure in which a needle is inserted into the centre of a bone, usually the hip, to remove a small amount of bone marrow. The aspirate is smeared onto a glass slide for microscopic examination.

Bone marrow biopsy (trephine biopsy)
Removal of a small core of bone marrow under local anaesthetic. It is used to assess bone marrow structure, the number and distribution of all the blood cell types.

Bone marrow harvesting
A medical procedure which involves collecting healthy bone marrow which is stored and kept for a future bone marrow transplant.

Chemotherapy
The treatment of disease by means of chemicals that have a specific toxic effect upon the disease producing antibodies or work by selectively destroying cancer cells.

Haematological malignancy
Blood cancer

Haematologist
A doctor who specialises in the treatment of blood diseases.

High Dose Therapy (HDT)
High dose therapy followed by stem cell rescue or transplant is a standard treatment for patients with multiple myeloma. Very high doses of chemotherapy

is given, usually melphalan. The high dose melphalan destroys bone marrow and re-infusion of stem cells (transplant) is needed to replenish the bone marrow until it recovers and produces new cells.

Immunoglobulins
Immunoglobulins are proteins in the blood plasma which function as antibodies and play an important part in controlling infections

Lesion
Any pathological or traumatic discontinuity of tissue or loss of function of a part.

Leukaemia
A progressive malignant disease of the blood forming organs marked by a distorted stage of the disease proliferation and development of leucocytes (white blood cells) and their precursors in the blood and bone marrow.

Lymphoma
A malignant tumour of lymphoblasts (blast cell) derived from B lymphocytes (white blood cell) most commonly affects children in tropical Africa.

Monoclonal Gammopathy of undetermined significance (MGUS)
The most important differential diagnosis in multiple myeloma is MGUS which means a paraprotein level exists in the absence of multiple myeloma. These patients are monitored as this can transform into multiple myeloma or other associated diseases (e.g. lymphoma).

Monoclonal proteins
Proteins made by cells which all belong to the same clone are identical and called monoclonal

Multiple myeloma
A cancer of red bone marrow characterised by an abnormal increase in the growth of plasma cells in bone marrow, osteolytic bone lesions which may or may not be present, and the appearance of monoclonal proteins which may be found in either the blood serum or urine or both.

Neoplasm
New and abnormal growth of tissue that may be benign or cancerous.

Osteolytic
Characterised by or causing osteolysis or dissolution of bone applied especially to the removal or loss of the calcium of bone

Paraprotein
These are abnormal immunoglobulins or antibodies produced by a clone of cells of the B-cell type for example in multiple myeloma. It's presence in the blood acts as an important marker of disease.

Paraproteinaemia
The presence of abnormal proteins in the blood.

Plasma cells
Normal plasma cells are found in the bone marrow and produce antibodies to fight infection. In multiple myeloma the malignant plasma cells produce large amounts of a single abnormal antibody that does not fight against infection (cloned cells).

Plasma cell leukaemia
A classification of multiple myeloma where there is a high number of circulating plasma cells which means there is peripheral blood involvement.

Plateau phase
Stable stage of disease in multiple myeloma following a good response to chemotherapy.

Progressive disease
Myeloma-related organ or tissue damage continuing despite therapy or its reappearance in plateau phase (Smith et al 2005).

Radiotherapy
The use of high energy radiation (usually x-rays) to kill cancer cells while doing as little harm as possible to the healthy cells. It works by targeting cells that are rapidly dividing and damaging them so that they cannot survive or reproduce. Radiotherapy is used for lytic lesions which are at risk of or have fractures and is highly effective in treating local symptoms such as bone pain or spinal cord compression.

Relapse
Reappearance of disease in patients who have previously had a response to treatment, including the detection of paraproteins in the blood or urine, or a rise in levels of paraproteins following plateau phase.

Remission
Restoration of the blood, bone marrow and general health of the patient to a relatively normal state induced by chemotherapy or radiotherapy. Patients with multiple myeloma must be monitored in case the disease returns. Remission is usually referred to as stable disease.

Stem cells
The most primitive cells in the bone marrow from which all the various types of blood cell are derived.

Stem cell rescue (Autologous Stem Cell Transplant)
Rescue is the preferred term when using the patient's own marrow or peripheral blood stem cells which have been collected and stored at an early stage. Also called Autograft.

Supportive care
Supportive care is general term for all services that may be required to support patients and their carers. This includes self help and support, user involvement, information giving, psychological support, symptom control, social support,

rehabilitation, complementary therapies, spiritual support, palliative care, and end-of-life and care of the bereaved (NICE 2004).

Sources: *On line Medical Dictionary* (1997-2007) University of Newcastle upon Tyne: The Centre for Cancer Education. *Haematology 13th Annual National Conference Advanced Haematological Nursing* (2003) Hammersmith Hospital, London.

Chapter 1. Background to the study

1.1 Introduction

This grounded theory research was an exploration of the experiences of individuals living with the incurable and progressive bone marrow cancer multiple myeloma, which is poorly understood outside the haematological oncological arena. Chapter one commences by providing a definition of the core category (*Contention*) that emerged from the research and its relation to impact on life and supportive care needs. The impetus for the study introducing the researcher's background and clinical area follows. This is pertinent because the experience of working on a chemotherapy day care unit inspired me to undertake the project. An overview of multiple myeloma is then presented describing various classifications, clinical features and common treatments, aims, outcomes and implications of treatment. Justification for the research, policy context, study aims and objectives are also addressed and finally a summary concludes this opening chapter.

1.2 The concept of contention

The findings that emerged from this research are associated with the impact of a cancer that is physically and emotionally incapacitating due to the presence of bone disease and immunodeficiency. *Contention* was the core or central category that emerged from the research data identified through its frequent appearance and explanatory power. *Contention* is presented as a concept relevant to nursing that enhances understanding of the difficulties encountered by individuals and their families particularly during stressful events or when supportive care needs are either not recognised or not met. A concept analysis was undertaken in order to develop a theoretical definition of *Contention,* discussed in more detail (5.3). *Contention* in terms of living with multiple myeloma suggests 'struggle', 'battle', 'disruption' and 'disharmony'. It is a multidimensional concept encompassing sociological, psychological and physiological manifestations.

1.3 The researcher's perspective

At the beginning of the PhD journey I wrote an account of my clinical practice area entitled 'Chair-side nursing' (Appendix 1) which describes the chemotherapy day care unit, the patients and staff who provided the inspiration and impetus for the research. My professional role is that of a clinical trials coordinator. The majority of trials I have been involved with relate to the use of single and combined chemotherapy agents for patients with multiple myeloma. Although the nature of the work lends itself to huge amounts of necessary administration with a focus on data collection and record keeping there is also a substantial nursing component. This means spending several hours during a working day with the patients attending the day care unit administering chemotherapy, and collecting various specimens (blood, urine, bone marrow) for local and central laboratory evaluations.

1.4 Dual role of nurse and researcher

The boundaries that normally exist between the roles of researcher and nurse appear to overlap which makes this particular post (clinical trials coordinator) unique. This is partly because clinical trials in oncology have become the norm and there is no 'treading on anyone's toes'. Being there as a 'research person' is acceptable and it is implicitly understood that while attending to the patient I also take on the responsibility of a trained nurse because I am invariably looking after very sick people. Patients living with multiple myeloma may arrive on the day care unit depressed, distraught or extremely ill and barely able to walk. In these circumstances the role of the nurse supersedes that of the researcher and research activities or 'run of the mill' procedures are put on hold.

In a previous job as a clinical trials coordinator in thrombosis research I was involved with trials which focused on prophylaxis for patients undergoing hip and knee surgery. I was often made to feel like an intruder and did not feel very welcome on some of the hospital wards. One ward sister finally accepted my presence when she saw that I was prepared to stop collecting data and get someone a bedpan. The fundamental difference between oncological and thrombosis trials is that one aims to extend the person's life while the other aims to reduce the risk of a post operative complication (albeit a deep vein

thrombosis which could potentially lead to a fatal pulmonary embolism). The fact that some of the trial medications are considered to be experimental has no bearing in the field of oncology where it may be looked upon as a potential miracle cure or at best another reprieve. Patients informed of treatment options can choose between not participating in a trial and receiving a standard or traditional therapy, or participating and receiving a new combination of standard therapies, or participating and receiving a completely new therapy (unlicensed drug). Some patients simply run out of options having had several lines of conventional therapy and the only path left open will be the new treatment. Spending much of my time on the day care unit administering chemotherapy to the patients has meant that I have become 'part and parcel' of the day care unit staff although my role is that of a 'research person'. I wear a nurse's uniform. Wearing a nurse's uniform was something I deliberately chose to do so I could 'blend in' and not feel like an 'outsider'. It was important that I did not appear to be different from my nursing colleagues working on the day care unit. It also prevents any confusion as to who I am. For instance, a patient I met for the first time wanted to know if I was a "proper nurse" because I was not in uniform. Furthermore there are the practical aspects of the job, issues of hygiene, infection control, health and safety when obtaining blood samples or handling cytotoxic drugs and the need to wear protective clothing.

1.5 Attending the chemotherapy day care unit

Patients coming to the day care unit for the first time are usually apprehensive. They and their families are not only coming to terms with the diagnosis of cancer but are trying to get used to the idea that they are going to receive some form of treatment and this will mean making changes to their normal routine. A newly diagnosed patient is given huge amounts of verbal and written information in a short space of time often during one or two visits to the clinic. This can be extremely overwhelming for some while for others it is welcoming and reassuring. High levels of anxiety can arise because of the adaptations they must make to their lives. It can be particularly stressful when patients have dependants prior to the onset of the illness such as young children, elderly parents, or a spouse who needs care and would normally rely upon them.

Receiving cycles of intravenous chemotherapy may involve travelling to the day care unit twice a week for two out of a three-week cycle, for example. Other supportive medical care may be required between treatments such as blood or iron infusions. The illness, the treatment, and the associated travelling can cause extreme tiredness and fatigue. Getting to the day care unit, receiving the treatment, and getting away to spend the rest of the day doing normal things becomes the main objective, even if this means resting for long periods at home. The main focus for all patients is whether or not the treatment is working. Newly diagnosed patients often assume that this will be so. However, for those who are 'fully trained', that is they have already received several lines of therapy, know that this is not always the case and are familiar with the unpredictable path of the disease and its response to treatment which is discussed in more detail in the next section on multiple myeloma (1.6).

The chemotherapy day care unit is often overcrowded with people. Nurses and doctors are seen walking in every direction. Nurses may be cannulating patients, taking blood samples, or setting up infusions. Doctors might be examining patients; phones are ringing constantly; bleeps are bleeping; patients are having treatments or they are waiting to be seen. Patients are treated and then go home. Alternatively patients become too ill to go home and are transferred to a ward. Amidst the 'hustle and bustle' of the day care unit environment a patient left waiting may start shouting or burst into tears and it is not until there is such an emotional outburst that anyone is aware that something is wrong. Some patients remain quiet while waiting to be seen, while others talk together often about their illness, their treatment, and whether or not they feel they are making any headway. There are patients who will tell a nurse without being questioned that there are problems such as the physical side effects from the medication (chemotherapy), or that they have depression. Sometimes patients do not want to make a fuss; they see how busy the nurses and doctors are, and as a result of this they remain quiet. However, it cannot be assumed that there are no problems. Patients participating in clinical trials are usually keen to report any side effects or adverse events because they appreciate the importance of collecting information and how it will affect future patients and the way in which the illness is treated.

1.6 What is multiple myeloma?

Multiple myeloma is a haematological malignancy or neoplasm characterised by an abnormal increase (cloning) in the growth of plasma cells in bone marrow, osteolytic bone lesions which may or may not be present, and the appearance of monoclonal proteins which may be found in either the blood serum or urine or both (Hoffbrand et al 2001). The 'cloned' plasma cells (myeloma cancer cells) produce immunoglobulins (antibodies). Their normal counterparts (immunoglobulins or antibodies) are thus significantly decreased resulting in an immune system that becomes compromised leading to recurrent infections. The cancer is complex and diverse and can be extremely debilitating due to bone disease. Sirohi and Powles (2004:875) describe the activity of the disease as:

"Intricate interactions occur between the bone-marrow microenvironment and the myeloma cells, frequently causing bone destruction which in turn stimulates tumour growth".

Numerous bones can be diseased with myeloma cells hence the term 'multiple'. It is not something that can be seen or detected easily unlike other cancers, for example a breast lump or an obstruction (blockage) due to for example, a rectal carcinoma. Several areas of expertise may be required during the course of managing the disease for example haematologists, haematological nurses, orthopaedic surgeons, and chemical pathologists (Bradwell 2003). It has an unpredictable path with numerous periods of relapse and remission. A patient can die within days or weeks of being diagnosed on one hand and on the other can live for many years with a 'smouldering' myeloma that does not require any medical intervention (Bradwell, 2003). Despite the modern treatments of combination chemotherapy, high dose therapies such as melphalan and stem cell rescue multiple myeloma remains incurable with a median survival of between 3-4 years.

1.6.1 Incidence

The incidence of this uncommon form of cancer has more than doubled since the middle of the 1960s, which is almost certainly due to the wider use of specific diagnostic tests namely protein electrophoresis (blood serum tests) and bone marrow aspiration (Foerster, 1993). Multiple myeloma represents only 1%

of all cancers and has been reported in all ethnic groups. In the United Kingdom there are approximately 10 - 15,000 people living with multiple myeloma at any one time and there are about 3,500 patients diagnosed per year (King 2003). In America there are more than 45,000 people living with the disease and approximately 14,000 diagnosed annually. Interestingly it is defined as the "orphan disease" (Dalton 2004) implying that it has not received the kind of media coverage favoured by other more common cancers such as breast or lung cancer. It has a higher incidence in males and the majority of patients are over the age of 40 at the time of diagnosis. The median age of 63 has decreased (Schey and Pallister 2004) in recent years and there appears to be an increase in the number of younger patients. Myeloma is more common in the Afro-Caribbean ethnic groups than Caucasians or Asians. The cause has not been identified but certain contributory factors may be associated with myeloma such as: genetic factors; weakened immune system; exposure to particular chemicals; radiation and viruses (Morris, 2003).

1.6.2 Classifications

Multiple myeloma is classified according to the type of immunoglobulins (Igs) involved. The structure of each Ig molecule is made up of two heavy chains and two light chains. The Ig molecule itself is normal but sometimes these are altered due to disease or separated resulting in a rare heavy chain disease or the more common light chain disease. Light chains are also known as Bence Jones proteins and there are two types of these called Kappa and Lambda. Only one or the other is present. The monoclonal protein or paraprotein level found in the blood serum is IgG in two thirds of the population of myeloma patients; IgA in one third; IgM, IgD or IgE are rarely found but can exist on their own or coupled together meaning Biclonal. Figure (1) displays the percentages of these classifications based on monoclonal protein production or type of immunoglobulin involvement. The urine contains Bence Jones protein (Kappa or Lambda free light chains) in two thirds of the myeloma population and in some cases is present without a serum paraprotein (Hoffbrand et al 2001). It is therefore not unusual to see on the medical history page of the patient's case notes 'IgG kappa multiple myeloma' or 'IgG lambda multiple myeloma'.

Myelomas, the majority of which are secretory, are also classified in more

generalised terms such as symptomatic myeloma, asymptomatic myeloma (smouldering myeloma), and plasma cell leukaemia where there is peripheral blood involvement. The non-secretory myeloma is rare and there are no paraproteins found in either the blood serum or the urine making it problematic when assessing response to treatment and progression of the disease. Another classification and the most important differential diagnosis is a condition known as monoclonal gammopathy of undetermined significance (MGUS) which means a paraprotein level exists in the absence of multiple myeloma. This can however transform into multiple myeloma or another associated disease (lymphoma, amyloidosis) in 26% of patients (Singer, 1997) therefore these patients are monitored closely and may attend the haematology outpatient clinic 3-6 monthly for a blood test.

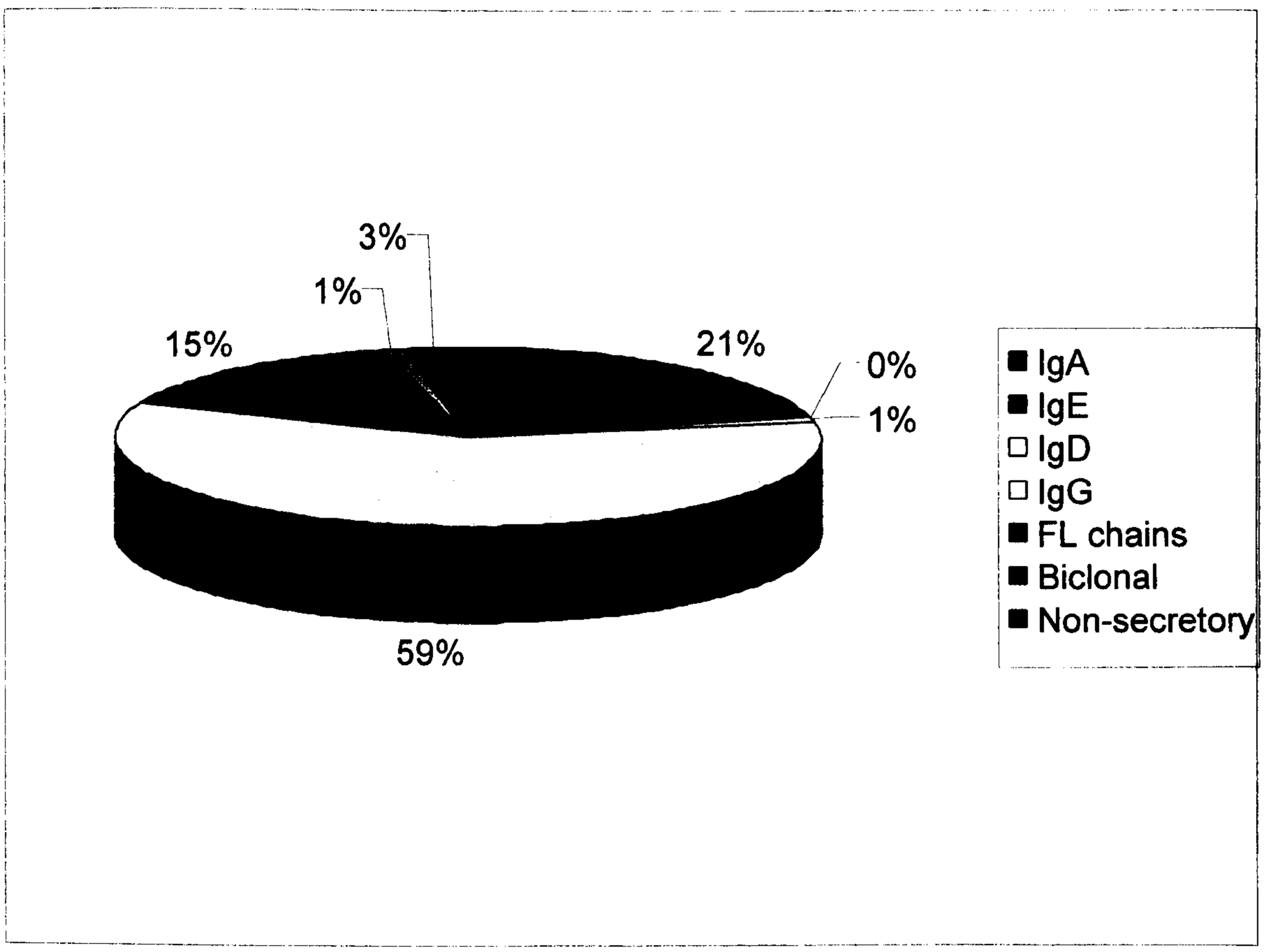


Figure 1 Classification of multiple myeloma based on monoclonal protein production. (Bradwell 2006: 62)

1.6.3 Clinical features

Clinical features vary according to the different types of myeloma. The most common of these are: bone pain, recurrent or persistent infection, renal impairment, and anaemia. One or all of these may be present however some patients are totally asymptomatic and diagnosis may be made following a fracture or a blood test for other reasons. Further clinical presentations include persistent and unexplained backache, height loss and osteoporosis (especially in males and premenopausal females) and spinal cord compression. Abnormalities such as thrombocytopenia, leukopenia, persistent elevated erythrocyte sedimentation rate (ESR), and hypercalcaemia may also occur (The UK Myeloma Forum Guidelines Working Group, 2001). There may arise in patients various presentations such as hyperviscosity syndrome with purpura, haemorrhages, visual disturbances, neurological imbalance, neuropathies, and heart failure which is more common in IgA, IgM, or IgD myelomas (Hoffbrand et al 2001). According to Foerster (1993) there appears to be a greater reduction of the normal immunoglobulin, in the IgG myeloma, more frequent infections, a higher serum paraprotein level, slower growth rates in tumours, less hypercalcaemia and amyloid disease than is present with other isotypes.

1.6.4 Treatment

Myelomas are often referred to as being in a state of 'relapse' or 'refractory' which means that the disease is not responding to treatment. Finding an effective treatment is often a challenge. It might only be achieved through persistent trial and error. Shain and Alsina (2004) argue that the disease remains incurable largely due to the mechanisms of drug resistance. Common treatments include chemotherapy, steroids, high dose chemotherapy, for example melphalan with autologous stem cell rescue (autograft), thalidomide and more recently bortezomib (velcade) and arsenic trioxide. Treatment with chemotherapy is indicated for patients with symptomatic myeloma. Medical intervention prior to the onset of symptoms has not proved beneficial (Hjorth et al 1993; Riccardi et al 2000).

The aim of treatment is to slow the progress of the disease to achieve a partial or complete response (sometimes there is no response) to therapy; control the

symptoms and improve the patient's quality of life (Morris, 2003). Treatment is aimed at reaching a 'plateau phase' where the paraprotein level falls significantly and remains at a level suggesting stabilised disease; or for the paraprotein level to fall to zero when the patient enters a remission period. Many patients are entered into clinical trials and have the option of receiving novel single and/or combination therapies. Radiotherapy is often used for lytic bone lesions, which are at risk or have already developed fractures, and is highly effective in treating local symptoms such as bone pain or spinal cord compression (Hoffbrand et al 2001). Bisphosphonates, such as clodronate and pamidronate are also given to control bone disease, hypercalcaemia, and may also have an anti-tumour effect (Cavenagh and Croucher, 2004). Transfusions or erythropoietin, which stimulates red blood cell production, are also given to treat anaemia.

1.6.5 The physiological impact of treatment

Treatment can be problematic due to the potential side effects or adverse events which can cause extreme anxiety and discomfort for the patient. Routine prophylactic medications given to patients receiving chemotherapy include anti-emetics, (for nausea and vomiting), anti-diarrhoea drugs, antacids to reduce gastric acidity, anti-viral drugs to reduce the risk of herpes simplex (cold sore) and zoster (shingles); anti-fungal lozenges and anti-bacterial mouth wash for oral mucositis which are all common side effects from chemotherapy. Infusions of immunoglobulins, oral broad spectrum antibiotics and anti-fungal agents may also be needed for recurrent infections. During treatment cycles many patients are treated in a chemotherapy day care unit. The disease, treatment and travelling can all add to extreme tiredness, lethargy and depression that have been evident in practice.

Repeated accessibility to veins can be difficult and time consuming when administering chemotherapy. Venous cannulation can be painful and phlebitis is not uncommon especially after repeated treatment cycles. Extravasation can occur if a cannula becomes displaced during administration (where the needle passes out of the vein and into the tissues) of vesicant cytotoxic drugs causing severe local tissue necrosis. A central line or catheter can be inserted into the

right vena cava or atrium for some patients having repeated treatments and has the advantage of reducing the possibility of extravasation and preserves peripheral veins. Common side effects of chemotherapy and other agents used can be particularly distressing for patients. Side effects include alopecia, gastrointestinal dysfunction, peripheral neuropathy, anaemia, and fatigue (Schey and Pallister 2004).

1.6.6 The psychological impact of treatment

Patients with multiple myeloma may have several lines of therapy and many become highly experienced and knowledgeable about the disease and treatment options. There is a huge focus on 'paraprotein levels' or 'M Bands' because these act as 'markers' by which patients can measure their response to treatment. They usually want to know if the therapy is working and need constant reassurance that it is. Paraprotein levels will drop significantly if the response to treatment is good. Alternatively they can remain static in which case there is no response; or it may rise significantly indicating disease progression. There is excitement and relief when there is a drop in paraprotein levels, frustration when the treatment does not appear to be making any difference and sheer despondency coupled with disappointment when the level rises. Importantly nurses are not always in a position to provide the psychological or emotional support needed by the patient and their family due to staff shortages and additional pressures or lack of appropriate skills.

1.7 Assumptions and context of care delivery

Healthcare professionals make many assumptions about what they think the patients are going through and what it must be like for them. In reality we (healthcare professionals) cannot possibly know what it is like and how the illness is affecting an individual and their lives or that of their families. Two publications have been written during the course of the project with the aim of highlighting a better appreciation of these issues. The first paper (Smith, Cox and Kelly 2007) aims to increase awareness and understanding of this relatively unknown cancer and includes a patient case study illustrating the impact of the disease on the individual. The second (Smith and Cox 2007) provides some insight into the often aggressive nature of the disease within the context of end-

of-life care. The narrative content portrays a dying mother and how the family coped with the illness and impending death. (Articles shown in Appendix 2).

If we (healthcare professionals) do not know what is going on in people's lives, how can we help them? If we do not know what is going on emotionally how can we understand why they are behaving in a certain way? How, in turn, can we become more sensitive to their needs? It might well be that a person will not wish to share life experiences with healthcare professionals, whilst on the other hand patients who do want to share their experiences and emotional problems may not have the opportunity to do so. The kind of environment in a chemotherapy day care unit may not be conducive because, for example, it is an open plan area with reclining chairs almost touching one another; spaces over flowing with people and examination rooms constantly in use.

Assumptions are usually made based upon an outer appearance and what people perceive as 'normal'. Patients with multiple myeloma often appear to look well. It can therefore be deceptive. It is not uncommon for individuals to camouflage or hide their true feelings when necessary. For example one male patient stated that he could not tell his elderly parents that he has cancer and has so far kept it from them. A female patient disclosed that she had been invited to a formal luncheon and her one fear was that she may have to take a wheelchair.

Another example, which heightens the layperson's perception, was brought to my attention while booking hospital transport for a patient. A member of the transport department informed me that there was no room for the patient's husband who always accompanied her when she came to the day care unit for chemotherapy. The member of staff working in the transport department stated that the patient always looked well and did not require an escort. The issue was quickly resolved following a discussion with the manager of the department. However the situation highlighted the fact that there are people employed within the hospital environment who have regular contact with patients and their families, and who have little or no knowledge of the illness, its implications or

supportive care needs. It can be argued therefore that there may exist a lack of understanding and sensitivity towards patients and their families.

1.8 Justification for the study

The justification for this field of enquiry was determined by the lack of qualitative studies undertaken. No studies were found relating specifically to the experience of living with multiple myeloma. Very few contributions were found when searching for nursing research and multiple myeloma (Coon and Coleman, 2004; Coleman et al 2003; Coleman et al 2002). The body of research mainly consists of randomised controlled trials, unrandomised trials, the management and treatment of multiple myeloma and quality of life issues. All of these are are of paramount importance because the main aim of these studies is to extend life and improve quality of living, however, they do not address in depth the supportive care needs of these patients.

The Cochrane Central Register of Controlled Trials currently has 973 articles relating to clinical trials and multiple myeloma (key search terms used on the Cochrane Database, March 2007). There are 4,801 records of multiple myeloma in the title, abstract or keywords in the Cochrane Data Base of Systematic Reviews (April 2007).

Quality of life questionnaires are commonly used for data collection for example the European Organisation for Research and Treatment of Cancer (EORTC) comprise of Likert scale answers for the patients to choose ranging from a score of 1 - 4 and 1 - 7 with the highest figure being the most positive response and the lower figure the most negative. Vast amounts of information are collected in this manner and although questionnaires are quick and easy to use they do not always take into account the complexities of human behaviour. This research which is a qualitative enquiry therefore, serves to complement the vast number of quantitative research projects in existence.

1.9 The policy context

The NHS Cancer Plan (2000) set out to improve supportive and palliative care for adults with cancer in collaboration with NICE (National Institute for Clinical

Excellence, 2004). Key topic areas include: communication, information, coordination of care, psychological, social and spiritual support. The experience of living with multiple myeloma required input from each of these parameters which was particularly relevant when considering an individual patient's unmet needs; implementation of service development and implications for future research. The purpose of this study was to provide a detailed description of the impact of multiple myeloma on that of the individual and the family, to enhance knowledge, and to inform clinical nursing practice. The ongoing challenges addressed in the *Cancer Reform Strategy* (Department of Health 2007) that were pertinent in this research related to delayed diagnosis and treatment; accessing life prolonging cancer drugs; difficulties in communication, ongoing support and accessing information. Collecting data on patients' experiences of cancer care was also indicated in the *Cancer Reform Strategy* (NHS 2007) which this grounded theory study contributes to. National and Local strategies for cancer and palliative care may have a substantial influence on clinical practice, however, the reality is that in order to succeed, high expenditure, resources and expertise are required. In haematological malignancies (NICE 2003), it appears there is a lack of research evidence to support some of the critical questions presented in relation to improving outcomes such as:

"*Is there evidence of better patient outcomes with early/prompt diagnosis compared with a delay in making diagnosis of haematological malignancies*"? (NICE 2003:7).

The evidence presented in this research suggests that delayed diagnosis in multiple myeloma may result in disease progression. Multiple skeletal fractures requiring surgical intervention (5.4.1) could potentially impact on the choice of treatment; thus reducing options because of toxicities associated with high dose chemotherapy and serious side effects. The implication is that early diagnosis can lead to prompt treatment of bone disease and a better quality of life.

1.10 Aims and objectives

The initial research working title for the project was 'Living with multiple myeloma: A study to explore patients' experiences and supportive care implications'. The aim of this study was to explore the experience of living with multiple myeloma from the patient and family perspective to determine their supportive care needs. This was an exploration of the participants' individual views. The primary objectives were:

- To explore the meaning of multiple myeloma in terms of becoming ill and being diagnosed
- To explore the meaning of living with multiple myeloma in terms of impact on the participant's personal or family life
- To explore the meaning of living with multiple myeloma in terms of impact on other family members
- To explore the meaning of living with multiple myeloma in terms of the participant's professional or working life
- To explore participants' perceptions of the health care and supportive care services.

These objectives have been achieved and the substance with findings are explicated in this thesis.

1.11 Summary

Chapter 1 has provided background information for the study. The impetus and inspiration for the project gradually evolved from the researcher's experience while working on a chemotherapy day care unit as a clinical trials coordinator specialising in multiple myeloma. The dual role of nurse and researcher has been discussed from the researcher's perspective. The research explicated in this thesis focuses on a unique cancer that is complex and understood poorly. It has a low profile in comparison to other cancers and evokes specific demands. It is these that form the focus of this research. This chapter has taken into account the impact of the illness, the treatment, and the impact of the treatment. Assumptions made in clinical practice; justification for the research; policy context; aims and objectives for the study have been introduced. Chapter 2 (Literature review) follows with reference to the literature review that preceded data collection in order to provide background information for the initial research proposal. There is a presentation of the subsequent updated literature review

undertaken after completion of data collection and within the context of the findings.

Chapter 2. Literature review

2.1 Introduction

The literature was reviewed at the time of the research proposal in 2004 and updated in light of the research findings in 2008. The cancer literature served to provide the background information and identified the void that was apparent. The methodology employed in this research was grounded theory, and to undertake an updated and extensive review of the literature prior to collecting the data and identifying an emerging central or core category, violates the basic premise of this approach. This is because the research design is aimed to generate theory that emerges from data and not from any existing knowledge (Glaser and Holton 2004). A summarised version of the review undertaken in 2004 is shown in Appendix 3. This chapter commences with returning to the literature in 2008 in view of the research findings, defines the scope of the literature search, the approach to the meta-synthesis of qualitative research, the meta-synthesis and summarises the current evidence.

2.2 The 2008 literature review

2.2.1 Returning to the literature

Returning to the literature towards the end of the study meant that I could consider a review in terms of the findings from this research, which are presented in Chapter 4. The 2004 review was undertaken with the aims of the research project in mind and two years before commencement of main data collection. My original research question was 'What is it like living with multiple myeloma'? At this time there appeared to be no qualitative enquires that addressed this specific question.

Four qualitative research studies (Carter et al 2004; Persson and Hallberg 2004; Mok et al 2003; Thome et al 2003) were identified and considered pertinent because they represented the patient and family perspective drawing from the experiences of dealing with various forms of cancer.

2.2.2 Scope of literature search

The CINAHL search results displayed a total of 1020 hits using the search term 'multiple-myeloma.mp' and yielded 6 results when combining named 'qualitative research designs', (Dahan and Auerbach 2006; Johansson et al 2005; Coon 2003; McGrath 2004; Bulsara et al 2004; and Herrmann et al, 1998). Only three of these

articles relate specifically to multiple myeloma. The remaining three concern haematological malignancies per se. MEDLINE produced 1016 hits using the search term 'multiple-myeloma.mp' and when combined with 'qualitative methodologies' or 'research designs' yielded a total of 5 hits (Jones et al 2006; Stephens 2005; Johansson et al 2005; Coon and Coleman 2004; and Herrmann et al 1998). Only three of these articles were found to relate specifically to multiple myeloma. Extending the search including the search term 'cancer.mp' yielded 2424 hits (CINAHL 1982-2008) and 958 hits (MEDLINE 1950-2008).

Returning to the literature in light of the findings was based on the following search terms: 'communication', 'impact on life', 'impact on family' and 'supportive care'. The literature is silent in relation to these topics in multiple myeloma. The papers selected for the synthesis were selected according to the following criteria:

- Topic relating to findings
- Qualitative research design
- Clinical practice area (blood cancers, other cancers, chronic diseases)
- Patient and family perspective
- Healthcare professional perspective.

The following synthesis aims to demonstrate relationships between the studies and provide new knowledge and understanding. Similarities and contrasts from the synthesis of pertinent qualitative research are compared to the findings of this research making a further contribution to the body of existing knowledge in the complex field of haematological oncological nursing. With the exception of the articles mentioned above, I was unable to find any further literature relating to multiple myeloma.

2.2.3 Approach to qualitative meta-synthesis

The meta-synthesis of qualitative research aims to address the main concepts in the literature that correlate to the findings. A synthesis is not just an amalgamation of related published research findings but the generation of renewed understanding or interpretation adding to that which is already known (Beck 2003; Britten et al 2002). The approach to this meta-synthesis is guided by the use of Noblit and Hare's (1988) framework of meta-ethnography and Schutz's (1962) levels of interpretation in relation to 'common sense and science' referred to as first and second order constructs. This approach was first suggested by Britten et al (2002).

Two of these authors (Britten and Pope) facilitated a one-day qualitative synthesis workshop at the University of Exeter (10/07/2007), which I attended and provided the guidance and inspiration for the approach taken.

Following completion of data collection eighteen relevant research papers were included in a grid (Appendix 4) under the main headings of 'communication', 'impact on life' and 'supportive care needs' representing three of the four main interrelating category groups that emerged from this research project. The fourth main category 'nature of disease' consisted of the subcategories 'delay in diagnosis', 'living with uncertainty', 'perceptions of disease' and from 'novice to expert patient' (gaining knowledge) all of which were found in the selected literature and are incorporated under the heading of 'impact on life' for the purpose of this synthesis. The grid (Appendix 4) includes details of each article including participants and setting to provide the context for the interpretations and explanation of each (Britten et al 2002). Listed representations of corresponding second and third-order interpretations from each paper are displayed in Appendix 5. The second-order as defined by Schutz (1962) are the original scientific interpretations by the authors and the third-order interpretations generated are presented in the form of conceptual hypotheses (Britten et al 2002). The qualitative meta-synthesis follows under the corresponding headings from the grid (Appendix 4): communication, impact on life and supportive care needs.

2.3 Communication

The first six qualitative papers on the grid focus on communication issues. The first two are concerned with the breaking of bad or significant news, one of which is from the doctor's perspective while the other is from that of the patient's. The remaining four examples are associated with how individuals respond to communication within the home and clinical environment, specific language used when ending active cancer treatment, interactions between patients and healthcare professionals, how parents communicate with their children and how much information is disclosed when mothers are diagnosed with breast cancer. Regardless of cultural differences and different health care systems in other countries the emphasis is on the experience of cancer, illness and disability, the impact on individuals, their families and the healthcare professionals with whom they interact.

2.3.1 Doctors breaking bad news

This study was selected because it was undertaken from the doctors perspective and although this may be viewed in terms of a limitation (excluding the patient and family perspective) it compliments the following studies. From the doctor's point of view, breaking bad news was perceived as both challenging and emotionally demanding (Friedrichsen and Milberg 2006). The study aimed to explore the experiences of doctors when telling patients with advanced cancer that treatment was being discontinued. This was viewed in terms of losing a certain amount of control regarding their ability to cope in a professional manner when dealing with difficult circumstances. Informing the patient that there was no longer going to be any further cancer treatment was perceived by the doctors as a reversal of the healing role to that of the role of the 'assassin' and the subsequent ramifications of guilt, helplessness, inadequacy and failure. This may have a fundamental impact on the relationship between doctor and patient/family particularly when the relationship is a close one. Patients with haematological malignancies, for example, establish relatively close relationships with consultants and nurses who are managing their care and treatments over a prolonged period of time, which may last for a significant number of years (McGrath 2001).

Friedrichsen and Milberg (2006) reports the difficulties doctors sometimes have communicating a negative message when complex relationships exist among close family members especially when they are unable to communicate with each other about the situation, for example, avoiding the reality of an imminent death of a loved one and protecting each other because it is too distressful. In some cases 'hope' or 'denial' can have such a powerful influence that individuals are reluctant to accept that there is nothing more to be done other than palliative treatment. The setting for this study was Sweden and doctors discussed interactions with patients from outside the country and for whom it was necessary to communicate through an interpreter. The doctors felt they had an ethical and moral duty to disclose all the information but believed that the patient's cultural backgound determined the type and amount of information likely to be delivered during the translations. Thus there was a potential for deliberate misinterpretation and the patient may not be informed about the gravity of their illness. Communicating bad news to individuals that doctors were seeing in clinic for the first time posed problems because of uncertainty, not knowing how they are likely to respond in the absence of prior

personal knowledge, which could only be gained through previous encounters.

Doctors in Friedrichsen and Milberg's (2006) study felt they were not always able to rely on scientific evidence and therefore relied upon their own clinical judgement and frequently considered their individual clinical experience to be more trustworthy. The scepticism was a result of inconsistency among published findings from various different papers and the knowledge that there was no guarantee that any one treatment regime would work effectively or successfully on any individual patient. Patients who gained knowledge through the Internet were sometimes more informed about novel cancer agents available than the doctors, which created frustration when family members demanded a specific treatment that may have been available in other countries. These encounters undermined the doctors' clinical judgement as it was considered virtually impossible to keep up with all the ongoing clinical trials and research worldwide. It therefore appeared that their medical competence and knowledge were being called into account. Questions relating to existential circumstances were sometimes a struggle to answer for example giving an exact period of time that an individual may survive or stating why that particular person had cancer.

Time and environmental disturbances during consultations were additional reported factors that contributed towards losing control of the situation when managing the breaking of bad news to patients and their families. Finding a balance is reported as complicated in a highly specialised clinical area because patients and families need the doctor's undivided attention when delivering significant news; while at the same time others (hospital colleagues) may demand immediate access to a clinic consultant for a critical situation concerning others. Lack of time implies that patients and families may have felt rushed. Unexpected interruptions sometimes disrupted the consultation exacerbating the experience of giving and receiving bad news further. For example doctors reported finding it difficult to return to the same level of concentration having been disturbed.

2.3.2 Patients receiving bad news

The second paper concerned with the giving of bad news from the patient's perspective (Randall and Wearn 2005) focused on six main themes: the character of the doctor, available time and attention, type of information and terminology

used, the ongoing process and regular follow ups, ongoing support and the setting or place where the news was given. This paper was selected for its relevance to the haematological clinic setting. Two out of fifteen participants were concerned that the information they disclosed during interviews may have been interpreted as criticism towards the healthcare they had received implying that the researcher (medical student) had a significant influence on the data collection. All participants were Caucasians which excluded individuals from different ethnic and cultural backgrounds which may have enhanced the study.

The findings suggest that patients prefer to have an honest and direct approach when hearing such information but it is also important that it is done in a friendly and professional manner by an individual known to be a cancer specialist. Contrasting experiences with consultants are reported. For example one patient was discouraged from asking questions because there were no answers, while another patient received a 'good' response to all questions. The majority of the patients (10 out of 15) spoke of the amount of time given to them during consultations and how much they appreciated not feeling rushed during busy clinic sessions. There were exceptions when patients felt that consultants hurried through clinic appointments and so did not feel that they were being treated as individuals. All the participants in this study stated that they wanted to know what the diagnosis was and it is suggested that information was not forced on them allowing them choice regarding amount of detail given. Those individuals that were given information leaflets reported having some control over the situation and could access information when and if they needed to, which was perceived as helpful. Abbreviations used in consultations such as "CLL" (Chronic Lymphocytic Leukaemia) and language that is commonplace in haematological terms such as "platelets" (Randall and Wearn 2005:597) had a significant impact on individuals resulting in confusion. However nurses were said to play a principal role reiterating and further explaining what had been divulged.

In this study (Randall and Wearn 2005) the main concern for patients during the ongoing process following diagnosis was that they would continue to be followed up and monitored. Due to the absence of visible symptoms they were unable to establish any significant changes or deterioration associated with their illness. Continuity and seeing the same person who initially diagnosed the individual was

viewed as advantageous and desirable. Alternatively there was a strong preference to see someone who was familiar with the medical history and whom they had met previously. Although treatment may have been non-curative it symbolized some semblance of hope on one hand, while on the other some patients felt they may be abandoned at some point in time. Participants did not feel qualified or appear to have the knowledge to participate in decision-making regarding treatment options (which perhaps is not surprising when individuals were newly diagnosed). However some participants who felt unqualified to make decisions regarding their treatment had been diagnosed for several years with haematological malignancies. This represented a complete contrast to patients I interviewed in the present study who were living with multiple myeloma; some of whom appeared to have developed from 'novice' into 'expert' patients.

Randall and Wearn (2005) addressed the provision of emotional support at the time of the diagnosis and during the illness which was provided mainly by the person accompanying the patient to the hospital. The majority (10 out of 15) had someone with them who also took on the advocacy role and kept other family members informed. Having someone with the patient was also perceived as an invaluable asset as the assumption was that an additional 'listener' was often able to take on board the content of the information provided which could be repeated at another time. This clearly indicated that there might have been a need for emotional support at the time of diagnosis for unaccompanied individuals. Access to nursing staff at any time was perceived as supportive and reassuring. The environment or room used for breaking bad news was not apparently an issue for the participants but when prompted, the key concerns were that the conversation should take place in a private but normal clinical consultation room and face-to-face sitting down with the person disclosing the news. The issues arising in the present study mirror at least some of these findings.

2.3.3 Responses to bad news

Byrne et al's (2002) paper centred on clinical communication which may ultimately affect the way individuals respond to a diagnosis of cancer and its aftermath. The main categories that emerged from this research were 'concealing distress', 'accepting' and 'rejecting the cancer'. This research also excludes participants from other cultural and ethnic backgrounds and does not reflect a realistic proportion of

the population from a multicultural society living in Liverpool.

The majority of participants (28 out of 30) employed strategies enabling them to masquerade their emotions which were considered to be too burdensome or distressful to share with others. Therefore the emotional needs of family and friends superseded those of their own. Family members often collaborated in going along with the facade. It is suggested that doctors may encourage family members to conceal their distress so that they do not display any signs of weakness in front of their loved ones as this would only serve to exacerbate their suffering. Conversations with doctors during clinic visits concentrated mainly on the physical aspects of the disease. There appeared to be a reluctance to disclose any information during consultations associated with personal concerns or emotions because patients perceived these as potentially undesirable and embarrassing, implying that it would portray unacceptable behaviour.

'Rejecting cancer' was associated mainly with negative emotional responses that the illness evoked and the effort or struggle to suppress these. There appeared to be a struggle or conflict between the suppression of emotions and the desire to liberate or unload them. Suppression of emotions was sometimes determined through individual coping mechanisms, uncertainty and ambivalence, or because of constraints in the heath care environment. The setting in one hospital, for example, was described as more conducive when compared to another enabling patients to sit at tables and talk which seemed to have a beneficial impact. The emphasis on staying positive has been encouraged by healthcare professionals but perceived as being discouraged from expressing how they (patients) were genuinely feeling. Thus they might not legitimately speak about issues that were considered negative, frightening or distressing. Maintaining normality or returning to familiar routines was considered imperative for individuals especially following surgery and treatment. A minority (6 out of 30) appeared to minimise the seriousness of the cancer and its consequences, which was demonstrated through nonchalant expressions such as "it was only a boob" in reference to mastectomy, and "there's plenty of people worse off" (Byrne et al 2002:18).

'Accepting the cancer' was categorised in terms of various responses such as living through phases of shock and bewilderment lasting for days, and in some cases

several years following diagnosis. Others reacted by trying to think of what may have triggered the disease. One patient recalled how she had bumped into something and hurt her breast prior to the diagnosis, which was where the cancer originated. Many lived in fear of an unknown future, recurrence of the cancer and imminent death. The "constant struggle with the fear" (Byrne et al 2002:19) was associated with the cancer and the emotional response to it such as how well they would cope psychologically if the cancer returned. Others focused their attention on preparations and future arrangements concerning the family and home environment to maintain normality for the children. Some participants viewed the situation as inevitable, accepting that the cancer existed and they just had to get on with what ever was necessary. In other words, nothing could change the fact that the cancer existed and the best solution was to eliminate it by whatever means at their disposal, and as quickly as possible.

Byrne et al's (2002) study also suggested a re-evaluation of life which involved incorporating the illness into a renewed meaning. Cancer impacted in such fundamental ways that priorities had completely changed. There was no longer time to be wasted on worrying about trivialities, for example, putting life into perspective meant concentrating on existential notions such as happiness and the value of living. This type of response therefore represented a totally different view of life following the diagnosis of cancer.

2.3.4 Language and interpretations

The study by Friedrichsen et al (2002) explored what patients understood when they had received information that related specifically to the ending of cancer treatment. Patients with incurable or progressive cancers, for example, might be treated with aggressive chemotherapy agents and radiotherapy with the aim of stabilisation of the disease and prolongation of life. Ending treatment was therefore interpreted by the participants as waiting to die. This study is pertinent because it relates to the issue of complex terminology, one of the key issues in the findings in Chapter 4. The palliative context (incurable cancers) and the meaning of language were significant in relation to participants living with multiple myeloma. Language and understanding may vary from one culture to another. This research was undertaken in Sweden and the findings may not be applicable in other health care settings.

The doctor's choice of words and expressions appeared to have a significant impact on how the information was interpreted. The three categories of words and phrases that emerged were grouped under the headings of: *Indirect warnings, Emotionally trying and Fortifying and supportive.* Indirect warnings were subdivided into *forewarning*, *evasive* and *ambiguous*. Forewarning was generally a prerequisite for news that the recipient did not want to hear and aimed to prepare them for what was to follow. The message was sometimes evasive, for instance when discussions related to transferring from oncology to palliative care was apparently done without clarifying the rationale supporting the decision. Ambiguity of words used often created confusion and misunderstanding which had the potential for different interpretations. Examples of ambiguous terms are 'cost' and 'progression'. Cost may be interpreted as meaning expensive in relation to finance or quality of life and individual suffering. Progression of disease means that the disease is worsening but in normal lay terms 'progression' is understood as advancing or succeeding and has a positive outcome. Words and expressions used that were emotionally trying were divided into *threatening and abandoning.* Patients felt particularly threatened when hearing information that related directly to a calculated amount of time given for their survival. Abandoning words were used when conveying to the patient that everything had been tried in terms of treatment thus the cancer would be left to run its course without any further medical intervention. Despite being told about the ongoing symptom control and palliative care participants continued to feel abandoned.

Fortifying and supporting words encompassed the concepts of *strengthening and confirming.* *Strengthening* dialogue consisted of comforting words that reassured and supported the patient iterating a positive message. Strengthening words aimed to inspire hope and encouragement dispelling concerns about the incurable nature of the cancer; the focus was placed on treatment. Confirming words used by the doctor during discussions with the patient suggests that the individual had the doctor's full attention, for example, the doctor was listening and verifying understanding.

The *Focus of messages* category was subdivided into *a treatment focus, a quality of life focus, and a threat and death focus.* The key message was discontinuation of treatment for the cancer and the rationale for this decision. Not all participants were

able or willing to give detailed accounts of their interpretations but were aware that treatment and surgery were no longer an option. Quality of life changed significantly with the discontinuation of chemotherapy and associated severity of side effects, which was perceived as living a more normal life. There was less emphasis on the disease and more on the person's well-being and quality of life. Threat and death messages encompassed *time, ultimatum, separation and death*. The main focus relating to time was survival. Patients who were given an exact amount of time that they were likely to survive felt extremely threatened and vulnerable. It was suggested that doctors may have adopted a 'bargaining' approach offering extended treatment providing patients met certain criteria such as significant weight gain within a set period of time which was viewed as a "threatening ultimatum" (Friedrichsen et al 2002:327). The focus on separation related to transferring of care from acute to palliative and leaving the specialist cancer doctor and familiar healthcare environment. This was experienced as traumatic because patients were disengaged from the healthcare professionals they had confidence in and had been a constant source of contact. The message that focused on death was described as ominous and frightening leaving the individual devastated with no semblance of hope.

2.3.5 Interactions during treatment

Bakker et al (2001) explored interactions between female patients and healthcare professionals during the time they received chemotherapy as outpatients. This study may have been strengthened with the inclusion of male participants providing a more complete 'picture'. The main categories that emerged from this research are the *nature of the information exchange* and *relationships.* The nature of the information is explicated in terms of *interaction modes* and *the power of information.* Routine clinic visits prior to administration of chemotherapy were described as "medically focused" (Bakker et al (2001:64) with the doctor doing most of the talking, performing a physical examination and reviewing laboratory test results. The 'doctor' mode of interaction was normally a question and answer session initiated by the doctor with emphasis on the physical well-being of the patient. The main objective was centred on symptoms and response to treatment. Participants felt reluctant to discuss additional non-physical issues or individual concerns that were for instance existential or psychosocial in nature. The 'nurse' mode of interaction was different to the 'doctor' mode because these encounters

included solving problems together and discussions about how the patients were coping at home. It was generally perceived that the nurse concentrated on the individual as a human being and not just a disease. During some of these encounters, the patients did most of the talking and the nurse was their main contact who could be reached by phone at any given time. The power of information enabled the participants to have more control and communicate more effectively with the healthcare professionals. Patients expected the healthcare professionals to provide adequate information and share their knowledge and expertise. If this was not forthcoming then it was understood as the healthcare professionals "keeping tight reins on power and control" (Bakker et al 2001:65).

Relationships were discussed according to roles and responsibilities. The oncologist was perceived as the key professional providing information that specifically related to medical matters such as the disease, treatment options, response to treatment and likely outcomes. Individuals expected to gain guidance and confirmation from the oncologist when accessing external sources of medical information such as the Internet or mass media. The nurse was perceived as facilitator, advocate, interpreter, main contact person and communication link between patient and doctor. However despite this system providing open access to the nurse conflict existed when individuals believed that specific information had not been passed on to the oncologist and the nurse was perceived as acting independently.

The participants viewed their own roles and responsibilities as patients to be on more common ground with the professionals. This meant that they needed to be assertive, kept fully informed and gain knowledge. The aim suggested but not always achieved was to be in a position to actively participate when communicating and interacting with healthcare professionals. All the participants related to a quality of *connectedness* associated with the conscientiousness in which patients and healthcare professions connected and interacted as a partnership. Connectedness existed when there was trust, mutual respect, partnership, and acknowledgement of patients' feelings, beliefs and psychological needs. If the connectedness was not apparent the partnership was nonexistent and the patient tended to adopt a more submissive role.

2.3.6 Talking to children about cancer

One of the significant issues that emerged from the present study was communicating with young children about the cancer (4.7.1). Some parents appeared uncertain as to how to explain about a cancer that they, themselves were struggling to understand and come to terms with. Barnes et al's (2000) research relates to 32 mothers with breast cancer and a total of 56 school aged children. This study also excludes male patients (fathers with breast cancer). The majority of participants were biased towards middle class. The findings therefore may have yielded contrasting results with the inclusion of mothers and their children from more deprived and lower working class backgrounds.

Timing of disclosure was a significant finding as parents chose to inform their children at specific times such as following confirmation of diagnosis or at the time surgery was planned. There appears to be a desire to inform the children when the diagnosis is known on one hand, while on the other disclosing information was delayed until the last possible moment. There was substantial variation in the amount and nature of information given to the children concerning the illness and potential consequences. For example 32 out of 56 children were informed that their mothers' illness was cancer.

The most common reason suggested for withholding information from their children regarding the illness was that parents felt they could not cope answering their children's questions especially those that may have related cancer to death. It was perceived by some parents that their children would not be able to cope with the information and that it would be too distressing or worrying for them. Other reasons for nondisclosure were the child's perceived level of knowledge and understanding. It was assumed that the word 'cancer' would have an insignificant impact on a 6 year old for example. Information was also withheld when special family occasions or the festive season was approaching because parents did not want their children to be anxious or worried during these particular periods which would spoil their enjoyment. While some mothers talked about protecting their children, others spoke of their children having the right to know about their mother's illness. It was considered important to talk about the illness and how they were feeling as a family and it was felt that children would lose their trust and become resentful if they discovered that they had been excluded from this information.

Parents also considered that their children would cope better emotionally and be more prepared for potential outcomes if they were included in family discussions about the illness and its implications. The mothers in this study suggested ways of helping parents to communicate more effectively with their children. They needed guidance on the most appropriate language to use when comr icating with their children about cancer. There was uncertainty about a child's level of understanding concerning illness and death and parents needed advice about communicating in a more effective manner particularly with very young children. A crèche or similar facility for the children at the hospital was suggested providing space for children to play, socialise or support one another. Furthermore if children become more familiar with the healthcare environment, it was reasoned that this would serve to alleviate their fear of the unknown, reduce anxiety and prepare them emotionally for the experience.

2.4 Impact on life

The next six papers were selected in light of the findings reported in this thesis regarding illness and its impact on life. The first paper illustrates the magnitude of change and disruption to family life from a caregiver's perspective. The remaining five papers focus on terminally ill patients' perceptions on the quality of their lives; delay in diagnosing disease and how this impacted on daily living; experiencing recurrent cancer; the impact of cancer on men and their roles as fathers and long-term survivors treated with bone marrow transplantation and their quality of life. Each have relevance to the demands of multiple myeloma and are therefore considered relevant to the review.

2.4.1 Disrupted life

Houldin's (2007) study highlights the apparent disruption caused in the lives of people caring for recently diagnosed patients with advanced colorectal cancers. This study was important because it provided the family member's perspective. The caregivers represented 12 spouses and 2 friends. This study is also biased towards middle and upper class families thus excluding other groups who may be underprivileged and vulnerable. The core or central category that emerged is stated as *"Balancing care giving activities and disruptions while dealing positively with daily disruptions and personal impact"* (Houldin 2007:325). Evidence suggests that total disruption was experienced and that this impacted on all aspects of life. Life

completely changed and the change was perceived as radical and abrupt. Individuals struggled with undertaking additional responsibilities and change in daily routines. There appeared to be uncertainty about making future plans such as arranging a holiday, accepting invitations or planning on having a family. Uncertainty was also associated with response to treatment, financial income, accessing life insurance and a shared future together. The personal impact of the diagnosis was immense and participants explicated their feelings in terms of experiencing helplessness, frustration and struggling to come to terms with the impact of an illness they had no control over.

Gaining knowledge and expertise about the cancer and treatment was considered a prerequisite for understanding how to manage as the primary caregiver and communicate more effectively with healthcare professionals

Young families felt particularly stressed because their children were young and they were at the peak of their careers. It was evident on attending the hospital for chemotherapy that the majority of patients appeared to be in the older age groups or retired which did not go unnoticed by the younger participants. The role of the caregiver was described as burdensome with serious emotional and physical manifestations such as depression and lack of sleep. The most distressful times were when individuals received the diagnosis, when surgery was planned or having to deal with numerous different hospitals. Receiving chemotherapy treatment and attending one hospital was considered less stressful as was getting back to a more normal pattern.

The cancer was typically symbolized as a battle zone by some of the participants such as “we are at war” or “we can use our energies in a more positive area, to fight the illness” (Houldin 2007:326, 328). There were reported positive and negative impacts on relationships. Couples disclosed a closer and more intimate relationship or one where they became kinder and more considerate to one another. Others suggested significant behavioural changes in their loved ones such as being irritable or constantly angry and bad tempered which proved particularly stressful for the families. A beneficial impact on sexual relationships was reported where sexual activity was heightened between treatment periods and it was felt the illness had brought couples closer together. Negative standpoints relating to sexual

relationships included statements that suggested their active sex life had come to an abrupt end; lack of desire because of stress levels; fear of physically hurting or exhausting their partner, or worry associated with risk of infection and low immunity.

Impact on social life appeared to be more constraining for some participants than for others. Not being able to socialise with friends and go out disadvantaged some as this was viewed as restrictive, while remaining at home relaxing in front of the television was appealing to others. Working life was affected because of absenteeism and there was apparently a struggle to find a balance between provision of care and other responsibilities or life commitments. Staying positive, striving to be optimistic and hiding emotions was described in terms of struggle. Thinking in positive ways despite facing the reality of the seriousness of the illness enabled participants to cope. The priorities of family life were of paramount importance for example being there to look after loved ones and taking care of the children. Participants used various coping strategies such as avoidance or denial and others were able to draw from their faith or religion. Some participants could cope by dealing with the present and not contemplating anything associated with the future. Talking to other people such as friends about the situation was especially supportive for some individuals. It is suggested that if the nature of the person undertaking the role of caregiver had a positive outlook on life, this personal characteristic could be sustained throughout the illness and associated challenges.

Keeping life as normal as possible for the children and maintaining the customary family routines was the key issue. Parents were worried and uncertain about talking to their children about the illness. The participants were also concerned about informing other family members about the cancer and how they would react to the news. Some of the participants were able to discuss the illness and treatment with their children and kept them informed of progress but avoided using the word cancer because of its association with death and dying. Parents adopted various approaches when communicating with their children such as speaking in positive ways, discussing the situation on a factual level, preparing children for the worst outcome, being creative and turning events into a story, or seeking help and advice from a counsellor.

2.4.2 Quality of life

This paper (Johansson et al 2006) centres on patients' perceptions of their quality of life living with incurable cancers while being cared for by a palliative homecare team. Despite the small number of participants (n=5) they participated in three focus groups while in the advanced stages of their disease and consequently only had a minimal survival time (end-of-life). This research was biased towards a motivated and purposive sample selection. The participants were described as active for a significant part of the day (50%) and there was emphasis on the positive aspects and the meaning of quality in their lives. Participants appeared reluctant to discuss existential matters and it may have been too distressing to disclose sensitive issues or speak of impending death within the focus group. Thus the complete reality of living with terminal cancer is not represented in this research.

The five themes in this paper consist of *valuing ordinariness in daily life, alleviated suffering, maintaining a positive life, significant relations, and managing life when ill.* The first theme concerning valuing ordinary things in life was discussed in terms of appreciation for a semblance of normality and being able to function in order to manoeuvre and progress with daily activities or go out with friends. Having the physical strength and feeling able to function meant that the individual was liberated from pain and fatigue. These periods of activity were crucial because they represented feelings of personal achievement and autonomy. Alleviated suffering related to physical and emotional well-being collectively with methods individuals employed to combat pain. Physical well-being was defined as being free from pain or other symptoms such as breathlessness or fatigue which could be exceptionally disabling. Finding a balance between rest and activity; being able to eat and sleep normally was understood to be the key to maintaining an acceptable level of existence with some quality of life. Emotional or psychological well-being was associated with the absence of physical discomfort and emotional disturbances such as depression or anxiety. In addition to medical intervention individuals employed their own strategies attempting to overcome symptoms such as pain by keeping occupied or distracted with specific tasks or offering to do something useful for another person.

Maintaining a positive life meant keeping enjoyable memories in the forefront of their (participants) thoughts and feeling reassured that they still served a purpose or that others needed them. It is suggested that focusing on memo that reflect a positive stage in their lives such as travelling abroad had a positive impact on the present creating temporary distraction or diversion from their reality. Feeling useful or needed was fundamental to the emotional stability and continued existence of the participants. Individuals had the explicit desire not to be perceived entirely as a sick person especially by family and friends that had been known to them throughout their lives. Significant relationships included essential networks and the development of resonance in communication with family and healthcare professionals. Family, friends, domestic pets, healthcare professionals, chaplains and fellow colleagues represented essential supportive networks. The hospital ward staff and the palliative homecare team provided ongoing professional support and the participants had access to nurses and doctors. The continuity of care and being able to recognise healthcare professionals and dealing with the same people was especially reassuring.

Resonance in communication implies good quality 'sounding boards' on both sides of the interaction and being actively listened to. Resonance in family communication therefore was perceived as a conversation that involved mutual collaboration and the sharing of problems so the focus was not always on the person with the terminal cancer. Resonance is defined in this paper as a powerful component of interaction that develops as a result of long-term relationships between patients with incurable cancers and healthcare professionals. Managing when ill related to being in control or being in charge of difficult situations and concentrating on the important things in life through the process of reflection. Taking charge required motivation, obstinacy and determination to go on living. It was seemingly crucial to remain positive and continue to make plans although some of these may have referred to specific arrangements following their death.

2.4.3 Delay of diagnosis

Denny (2004) reported on the experiences of women living with a chronic gynaecological disease known as endometriosis. The key domains of which were pain, delay in diagnosis and how their lives were effected by the disease. This paper was selected because it provided an example of the impact of a chronic

disease. Multiple myeloma may itself be viewed as a chronic illness and some of the findings appeared similar to those in the present study. For example, delay in diagnosis, impact on life, living with an incurable disease with recurring episodes, undergoing numerous periods of treatment and struggling with an uncertain future. The period of time between onset of symptoms and diagnosis in this research ranged between 3 months and 14 years. The majority of the participants attended their GPs while still in their teens and it is suggested that their doctors did not take them seriously. The pain women experienced was 'normalised' for example one participant was told that she was unfortunate and that she had been suffering with unusually severe period pains. The women were either prescribed oral contraceptives or were informed that there was nothing to be done. It was therefore something that they would have to endure. Normalisation of symptoms suggests that GPs were reluctant to contemplate potential pathological causes and failed to distinguish or recognise subtle differences in presentation.

Women were able to make distinctions between the nature of pain relating to normal periods and the pain relating to the disease. Although they may not have been able to articulate this at the time they first attended their GPs. The pain was described as intense, debilitating and in some cases continuous. Pain during sexual intercourse (dyspareunia) is a known and common symptom of the disease, however this research suggests that the topic was not generally addressed in consultations with the gynaecologist. The participants were not always prepared to initiate communication relating to sexual activity or relationships, which were considered private or they were too embarrassed to disclose. Dyspareunia was not always associated with the abdominal pain relating to the disease, which implies that it was considered by some of the participants as a separate and unrelated issue. The sexual problems experienced had a profound effect on the women's lives and that of their partners. Some individuals had a supportive and understanding partner but for others the strain resulted in deterioration in relationships and separation.

The participants stated a preference for surgical interventions (laser surgery) to vaporise the recurring growth of endometrial lesions and cysts. The women experienced unpleasant side effects from prescribed medication such as significant hair loss and severe bouts of prolonged menstruation (menorrhagia). Oral

contraception masqueraded symptoms and offered temporary relief for some of the participants.

The disease had a significant impact on the women's social and working lives. Social activities diminished entirely for some individuals. Family and friends provided constant emotional support and practical help for others. In the workplace there appeared to be a lack of understanding or recognition regarding the legitimacy of the illness, which was apparently trivialised by employers and fellow workers. Periods of absenteeism were therefore perceived unfavourably by employers who believed that the amount of time taken off (through illness) was unacceptable adding further tension and making life more problematical for the participants. Not all the women experienced lack of support and understanding in their place of work. Some employers were reported to be supportive, considerate and flexible allowing the women to arrange their working schedule to suit their lives and accommodate their illness.

Following surgical intervention the women perceived the future in terms of fear and uncertainty relating to recurrence of the disease and how they would cope. In this study one participant stated that her general health had significantly improved following a hysterectomy but two (n=15) women continued to be in disabling pain regardless of several years of treatment.

2.4.4 Experiencing recurrence

Howell et al's (2003) exploration of women's experiences living with recurrent ovarian cancer provided a sharp contrast to the experiences of people living with multiple myeloma and the periods of relapse and remission which represented the common link. For example the approach and attitudes of the healthcare professionals between the different healthcare systems towards recurrence (relapse) appeared to have opposing views on decisions regarding continuation of cancer treatment (chemotherapy) and sustaining hope. The findings relate to a specific geographic area in Canada and may not be transferable to other healthcare cultures.

The findings from this paper consisted of four main themes: *waiting for recurrence, facing the diagnosis of recurrence, managing treatment-related concerns, and*

attempting to regain control. Despite the knowledge that recurrence of the cancer was likely at some point following their first line of treatment, many of the participants perceived the 'waiting' as extremely frightening. Follow up appointments were therefore viewed in terms of trepidation and fear of what might be discovered. The anticipation of recurrence did not, in the actual event of a recurrence, prepare the women or lessen the shock and devastation. The exception (n=1) was that it was expected and therefore came as no surprise.

Information given at the time of diagnosis relating to recurrence of cancer and survival were sometimes given in statistical terms which was viewed as unhelpful as numbers were meaningless to the participants. Thus speaking in more simplistic terms or using straightforward language was inferred. It is also suggested that the participants may not have been prepared to take on board additional information relating to potential survival at this time because it appeared to overwhelm them. Discussions relating to statistics were described as provoking fear while attempting to cope emotionally with the diagnosis and consequent treatment ahead.

Waiting for recurrence related to the period of time following the women's first line of treatment and when they attended their follow up hospital visits which went from three to six monthly and progressed to annual appointments. The participants became acutely aware of the tumour markers (CA-125) that represented the potential recurrence of their ovarian malignancy. If the level was gradually rising for example, this was an indication that the cancer was recurring or spreading which symbolized devastating news for many of these women. The follow up appointment was expressed as a time of intense anxiety because it was reminiscent of a period that represented devastating news of cancer and this was usually anticipated. The women were aware of the potential consequences because they had prior experience and knowledge.

Facing the diagnosis again (recurrence) may have followed a period of several years but for some of the participants remissions appeared significantly brief which meant experiencing prolonged periods of ongoing treatment and unpleasant side effects from surgery and chemotherapy such as menopausal symptoms and extreme fatigue. Treatment-related issues at the time of recurrence were associated with distress and the apparent change in attitude participants perceived

from the healthcare professionals. The participants perceived a struggle to elicit further information from the healthcare professionals relating to treatment options which was not experienced when they were first diagnosed. Participants indicated that they were no longer being listened to. The general consensus appeared to be that recurrence was tantamount to a hopeless case indicating that there was nothing more to be done.

The women found that they had to assert themselves and act as their own advocates once they reached the status where they were perceived as being 'recurring hopeless and helpless cancer cases'. Some of the women changed their physicians for instance while others may have been restricted to specific treatments because of the area or location in which they lived. The 'watching and waiting' policies adopted by doctors during the time of recurrence appeared to take its toll and was an exceptionally fretful period for the participants. Strategies employed to overcome some of the difficulties resulted in the women doing their own research and searching for information which prepared them for making appropriate demands from the healthcare professionals and requesting the ongoing treatment they required. It was perceived by some of the women that having had multiple and combined treatments such as surgery, chemotherapy and radiation, there were very few options left regarding treatment during recurrence. Women also reported that their experiences of facing treatment again was daunting and coping with the symptoms from the disease progression and the side effects from treatment was difficult. In contrast some of the research participants living with multiple myeloma had advanced bone disease causing continuous pain that was often difficult to control. Similarly disease progression was a real threat and the numerous lines of chemotherapy were a constant battle because of toxicities.

Gaining more specialist knowledge about the cancer and how their bodies responded to the treatment enabled the women to become involved with the treatment decisions and communicate their concerns more effectively with the healthcare professionals. They gradually took more responsibility for themselves by becoming more assertive through desperation to gain some control over their progressive disease. Attempting to regain control was synonymous with development of knowledge and expertise. The women gained more experience and learnt about the various alternative and complementary treatments available.

Despite accessing alternative treatments on a 'trial and error' basis, this was viewed as having control by actively doing something which was considered better than doing nothing.

2.4.5 Impact on family

The aim of this paper was to explore gender and men's experiences of cancer, how illness impacts on family life and their roles as fathers (Elmberger et al 2002). This paper was selected because it focused on men as fathers with haematological malignancies. The researcher in this study was female and it is suggested that perhaps gender and age differences may have influenced the data collection. A male investigator, for instance, may have produced different findings.

During illness men viewed themselves differently. Transition related to a fundamental change in the participants self-image. For example transforming from an athletic and strong man to a sick and feeble individual. The transition was explicated as burdensome and difficult to tolerate because it related to their manhood and their father role. The findings of this research show how the men reacted to the transition and how they coped spending more time at home with their families. The role of the man who spent a significant amount of time away from his family home earning an income had been transposed into a sick father remaining at home with his family. The outcome of spending more time at home inevitably meant participants had more time with their children. The men sometimes underwent cancer treatment as outpatients during a normal working week and at this stage it was generally perceived by their families that they were at work as usual. Family life therefore appeared unchanged and the men apparently struggled to convince their families that the illness was serious.

For most of the men, their parental role was jeopardised by the presence of constant supportive partners and parents. A single parent however may not have the same constant supportive network. One of the participants in this research (n=8) with two young daughters was able to leave his children with his mother while he was in hospital stating that there was no one else to look after them.

The advantages of the changed father's role in relation to spending more time with the children included assisting the children with their school work and becoming

more involved with school meetings which the men did not have time for previously. These activities were perceived as positive strategies to regain some authority, motivation and control as fathers. The participants were also concerned about their children's changed perceptions of them as their fathers and the way in which they managed the situation in relation to the illness. It was important therefore that they (fathers) represented and sustained a positive image that would be memorable following their demise. It was difficult to disguise emotions or negative feelings during treatment with chemotherapy and experiencing some of the associated gastrointestinal toxicities and altered body image from these agents. The men reported reactions only occurred from their children when faced with dramatic changes in their fathers' appearances such as hair loss. Families were reluctant to visit the hospital during the men's hospitalisation because of their illness, altered appearance and attachments (intravenous lines) with which the children were unfamiliar. The men preferred to stay at home and not at the hospital during treatment when offered the choice. The hospital environment was described as gloomy and depressing by many terminally ill patients.

Additional strategies to regain control and restore their self-image as men and fathers evolved through gaining knowledge and making plans. Some men wanted to learn more in-depth about their cancer than others. An ambiguous desire to learn or not to learn more about the illness appeared to exist which represents a common link to the findings in this thesis. Another common element in this paper was the men's use of metaphors in relation to cancer and 'fighting the enemy'. Making plans and preparing for the future regarding family and financial security following their death gave the men a sense of purpose, responsibility and control.

Talking to the children about the illness was sometimes difficult because of the complexity of the cancer which is also a finding in the present research. When parents spoke to their children about the condition they often avoided the use of the word 'cancer' as it was felt this would be too upsetting. Children were sometimes perceived by their parents as uninterested or unconcerned about the illness. These assumptions were based upon their children not asking any questions. Some parents worked on a 'need to know' strategy not wanting to complicate issues or confuse their children. Others made decisions regarding how much information they were prepared to disclose to their children. One of the participants had a 13

year old daughter who was so traumatised about her father's illness and possibility of his imminent death that she was unable to concentrate on her schoolwork. Maintaining normal routines for the children was implicit although not highlighted as a central issue in this paper.

The men appeared to reprioritise and re-evaluate their lives as a result of having the cancer. Their focus was diverted to what they currently considered more important and valuable such as spending time with their families, being more involved with their children's activities, and aiming for a better quality of life. Prior to their illness their focus appeared to be on their work, ambition, expenditure and material gain.

2.4.6 Life following transplant

Molassiotis and Morris (1998) discuss the meaning of quality of life following unrelated donor bone marrow transplantation in the long-term adult survivors of chronic myeloid leukaemia. Questionnaires used in this study required the participants to write narratives. Some participants may have found this difficult or tiresome. Alternative approaches such as interviews may have generated more information.

The findings are divided into five main domains commencing with the participants' perceptions of their quality of life comparing with their life prior to the transplant (meaning of quality of life). The second domain is centred on the differences in daily life following transplantation. The third domain is associated with problems experienced by the participants at home following discharge from hospital. The forth domain relates to concerns about the future and the fifth includes recommendations from participants based on their personal perspectives that have potential implications for clinical practice

Responding to what quality of life meant to participants was explained in terms of normality and living a normal life. Comparisons with other healthy individuals who were fit and able were perceived as normal. Comparing life before and following the transplant facilitated the explication of the participants' views and definition of their quality of life especially if there was a significant deterioration in their capabilities as a result of extreme weakness for example. Being normal therefore was understood

as being able to undertake all the activities that the participants had been able to do prior to the transplant and in the absence of symptomatic disease. Quality of life meant being fulfilled, enjoying and appreciating the experience of living despite apparent restrictions in energy levels. Being healthy and independent with no signs of physical or psychological sequelae was ultimately linked to living a normal life. Sustaining normal relationships with family, friends and colleagues or fellow workers; being able to take care of the family; continue working and socialising; feeling happy, living in harmony and in a safe environment constituted the pertinent themes in this domain.

Differences noted in daily life when compared to life before the transplant was divided into three themes: negative impact, positive effects and no difference. The negative impact related to physical and psychosocial ramifications of the transplant such as increased fatigue, family problems and loss of employment. Positive effects related to a good recovery, re-evaluation and appreciation of life. No difference implied that life was exactly the same before and following the transplant. The difficulties that the participants experienced following discharge and returning home were associated with the physical disability caused by fatigue, not being able to work, socialise or make plans. The psychological impact manifested itself through frustration caused by the general weakness, memory of the transplant experience, fear of recurrence of disease, becoming infertile, impact on social life, loss of independence and worrying about financial constraints.

Concerns about the future included status of the participants' current health and the fear that the cancer will at some stage recur. Thus there was an emphasis on continued recovery and improvement but a constant presence correlating to a threat of recurrence. Participants had anxieties relating to the long-term effects from the transplant for example how long the side effects would last and whether or not they were permanent. Worries were reported relating to associated long-term use of prophylactic treatments in conjunction with adverse events for example hormone replacement therapy given because of forced premature menopause. Some individuals were therefore reflecting on the consequences of their treatment and a future without children. Others focused on concerns about a full recovery to their normal pre-transplant selves ("normalisation process" Molassiotis and Morris 1998:205). Future concerns were associated with coping financially, unable to plan

too far in advance, and caring for the family.

Recommendations suggested by participants in response to what they considered strategies that could be employed by healthcare professionals to enhance their (participants) quality of life included recognising their need for ongoing psychological support and reassurance. It was suggested that information and advice on medication, treatments and side effects was needed and continued help with physical symptoms. It was also recommended that more research was required to develop drugs with less toxicity. The psychological and physical impact of treatment and associated side effects in the present research suggested that it was not uncommon for individuals with myeloma to struggle with debilitating symptoms associated more with drug toxicities than the actual disease.

2.5 Supportive care needs

The final six papers selected associated with supportive care needs are intrinsically linked to the findings presented in Chapter 4 and complement the above research studies relating to communication and the impact of cancer on everyday life. The first paper (Botti et al 2006) explores the views of nurses working in haematological oncology wards concerning the existence of perceived 'barriers' that prevented them from providing adequate psychosocial support to patients. The second and subsequent papers focus on gender specific differences; treatment decisions and making choices; categories of support and access to financial benefits. Finally, Murray et al (2002) compares the illness trajectories of two different advanced and progressive diseases in relation to the participants' support needs and services available to them.

2.5.1 Support barriers

The study by Botti et al (2006) suggests the presence of emotional and professional barriers that existed in the provision of psychosocial support in haematological oncological nursing. The nurses that participated in this research identified five key concerns: an appropriate time to talk with patients; establishing a trusting relationship; dealing with patient's emotion and distress; providing continued support and ineffective communication.

2.5.2 Differences in gender

Clarke et al (2006) explored gender differences in patients with cancer in relation to their emotional support needs. This study only included married men and therefore excluded single men or those living alone. These groups may have required more psychosocial support. The results from this research suggest that female patients were more likely to seek or accept help for their emotional needs than men. It was also viewed that women were more likely to feel less satisfied with the support services available than men. Women appeared far more resourceful setting up a complete support network for themselves including family, friends and healthcare professionals. Female patients appeared to be more likely than males to understand that the clinics were busy which discouraged them from requesting support during consultations.

Regarding prioritisation of support the female patients with breast cancer had access to a specialist breast care nurse which facilitated meeting their support needs and provided a valuable contact. Other female patients with melanoma did not have access to specialist support and it was suggested that their emotional support needs were not usually acknowledged.

The male patients were more likely to seek emotional support from their wives or a close friend and not from the healthcare professionals. Men appeared aware that support was available if they needed it but viewed other kinds of information with reference to their illness or treatment more relevant to their needs. Unlike the female patients the men did not perceive the hospital staff as too busy at any time to talk. The male patients also thought that their wives may have benefited from emotional support themselves. There appeared to be dissimilarity in relation to gender and perceptions of emotional support. The men seemed to equate any friendly encounter or normal verbal exchange with the healthcare professionals as emotional support. When professionals provided information concerning hospital procedures or treatment, for instance, the men viewed this as emotional support because the information reassured them. Women may have had equal time and similar interactions with professionals but emotional support was defined as something quite different to the men. Emotional support for the women meant that the interaction with the healthcare professional needed to be more in depth and meaningful with a satisfactory outcome or resolution. The couples and families

interviewed in the present research indicated that emotional support was provided mainly by family members and close friends. One participant who lived alone attended a day care center at a local hospice and joined a patient support group which she found was particularly beneficial because everyone was in the 'same boat'; people had time to talk, listen and understand which provided the emotional support she needed. While others acknowledged that they may need professional help or counseling.

2.5.3 Making choices

Decision-making and attempting to make choices regarding treatment options may be daunting and inappropriate especially when patients are newly diagnosed. Ziebland et al (2006) explored women's experiences with ovarian cancer and how much involvement they had in the decision making process. These authors argued that patients might not want to make a decision alone and that they should be encouraged and left in no doubt as to what the consultant considered was the best course of treatment for them to have. It was surmised that to be offered choices without any advice or expert opinion was perceived as a form of abandonment.

The qualitative analysis was derived from some of the participants' interviews taking part in video recordings during the DIPEx project (personal experiences of health and illness). Videotaped interviews provide an accurate record of complex behaviour, facial expressions and body language. However, the presence of a camera or awareness of being filmed may have influenced or altered the participant's behaviour. Some of the experiences described had taken place several years before the interview which implied there may have been concerns with recall.

The findings highlighted three approaches to decision making in relation to making choices about treatment options. The first approach involved the women accepting the doctor's recommendations and 'going along' with any suggestion made. The second approach indicated more involvement in discussion and seeking further advice or second opinions; and still complying with the doctor's recommendations. Women utilizing the third approach appeared more proactive and made some decisions with reference to their treatment options. Decisions were sometimes based upon previous experience, for example refusing a treatment because of a

prior bad reaction to a specific agent and choosing an alternative option. It is suggested that women did not always perceive that they had been offered any choices relating to their treatment.

Women who 'went along' with the doctor's treatment preference without question did so because they may have been in a state of shock associated with being newly diagnosed. Some of the participants felt incapacitated, extremely unwell and in fear for their lives. Participants appeared to struggle with understanding why they were offered choices when they were newly diagnosed and in a "traumatized state" (Zeibland et al 2006:364). Others recognized they did not have the knowledge at this stage in order to make any decision relating to treatment options. The women who were more questioning and also 'went along' with the doctor's advice did so because it was felt that there was no alternative if they wanted to stay alive. Those who were able to make some of the decisions (minority) had done research having accessed internet sites and gained some knowledge and understanding of their illness and treatment options available to them. Women who had a recurrence of their cancer and who were more familiar with treatment options were better prepared to participate in decisions or negotiate their choices. Knowledge and understanding of how their bodies responded or reacted to previous chemotherapy agents also influenced the women's decision making as previously revealed. Decisions to refuse treatment were sometimes made by women who perceived that they were at the end of their lives or felt they could not tolerate further chemotherapy.

Making choices was sometimes perceived as burdensome especially if there was conflicting advice from consultants (surgeon and oncologist) who could not agree on the appropriate treatment. Participants also implied that their relationship with their doctors or medical team was a significant factor and if they did not accept their expert opinion it was possible that a sound relationship could be threatened. Some of the participants were offered a choice of single agent chemotherapy or combined chemotherapy (clinical trial) without full explanation as to why they were being offered the choice or providing a rationale for the different approaches. Women, therefore, did not always understand if the treatment approach was experimental or if evidence was required to establish which was the most effective option.

Decisions were sometimes influenced through the appreciation of other people fighting and campaigning for access to an expensive chemotherapy agent that was not previously available at the participant's hospital. Participants therefore may have felt an obligation to take up this option when offered and with gratitude. In this research it is suggested that the medical team may have been influenced by litigation cases in the mass media which resulted in a reluctance to state their preferences when offering treatment options regarding surgery and chemotherapy. This meant that the women were informed that they could have surgery but it was entirely up to them to decide with no further explanation or information to assist them in their decision-making. In contrast some of the participants were guided and persuaded with detailed information tailored to their needs of a suggested course of treatment and potential side effects.

2.5.4 Support categories

Furness's (2005) paper highlights the supportive care needs and experiences of patients who have experienced facial surgery for cancer and other conditions such as trauma. The aim of the research was to investigate individuals' perceptions of psychological support provided by healthcare professionals (Furness 2005). It is argued the main concern centers entirely on the surgical removal of the cancer and survival. From the healthcare professional's perspective the assumption was that facial disfigurement would be associated with psychological and emotional upset and that this was to be expected.

From a patient and family perspective, three categories of different types of support emerged: *informational*, *practical* and *emotional*. Information given pre-operatively relating to surgery, potential risks and outcomes were viewed as satisfactory. However being told the worst potential outcome resulted in increased levels of anxiety for some patients. Post-operative information described in terms of deficits identified a substantial void in the provision of guidance, advice or disclosure regarding the physical and psychological aftermath of surgery and support in the community. Patients reported, for instance, discovering that their surgery had been more extensive than anticipated which had not been explained and therefore they were not prepared. Post-operatively patients received no information that prepared them for some of the disturbing physical symptoms and problems they experienced with prosthetic appliances. Participants were rarely informed about support groups

by the hospital staff unless they had access to a specialist cancer nurse. They reported finding the information through other sources and indicated that support groups in the community were fundamental for their psychological recovery and adjustment. It was suggested that providing information and communicating with family or friends would help them to understand what was happening and enable them to support their loved ones following discharge.

Practical and material support were associated with disfigurement, prostheses, assistance with mobility and practical help at home. Although some of the participants stated that they had no practical help from the hospital staff, others received guidance on the application of devices and makeup to masquerade physical alterations. It cannot be assumed that practical support was not considered and it could be construed that the task may have been too challenging. Facial surgery may involve removing teeth and using breast tissue for the reconstruction. Patients were not always offered a prosthesis following reconstruction surgery. An identical scenario to the findings (4.25.2) was presented in this study in relation to the patient's spouse 'battling' to access support on behalf of his wife who was physically unable to speak. He was trying to get a prosthetic device for his wife's breast following hospital discharge. It was felt that the hospital staff could have been more proactive in providing practical support.

Emotional and psychological support was divided into subcategories of *availability and need,* and *components of support.* Participants either considered that all their needs were met or that they needed help and that it was not offered. The hospital staff did not appear to be perceptive to the participants' potential emotional needs. In other words participants viewed healthcare professionals as oblivious to their feelings relating to the psychological trauma and shock associated with the consequences of their surgery. It was suggested that having someone to talk with other than family would have made a significant difference to their emotional well being. Components of support were comprised of staff awareness and attitudes, ongoing support and having time to talk.

Participants suggested that in their opinion hospital staff did not appear to be aware of the traumatic impact of facial surgery or understand how it affected them in the long term emotionally and psychologically. It was suggested that the healthcare professionals were inadequately trained to deal with the patient's emotional

responses, lacked the necessary counselling skills and knowledge needed for appropriate referral in the community. Establishing a relationship with healthcare professionals was determined through how approachable they were and whether or not they were perceived as having a trusting and caring personality. These characteristics were perceived as essential and positive in relation to accessing emotional support and feeling reassured. Impersonal or negative encounters with healthcare professionals often resulted in low self- esteem and feeling unsupported.

Ongoing support requiring long-term follow up was addressed by several of the participants. Specific points in time were identified when emotional support would be beneficial. These times were following surgery and again following discharge when the individual's need arises. The interim period was identified as a time of shock and coming to terms with the aftermath of the surgery. Patients recognized that they continued to need support during the long term and felt isolated and depressed having left the hospital. However, home visits from GPs and district nurses following discharge were cited by some participants as providing support and greatly appreciated. Hospital staff were often perceived as too busy with no time to talk and provide emotional support. This meant that when staff were able to spend time with the patients, it was during an occasional and infrequent quiet period. Participants felt that it was inappropriate to elicit emotional support from the surgeons or take up too much of their time. The ward staff were perceived as constantly occupied with the pre and post routine care associated with the busy operating schedules. The findings in the present research also suggested patients and families perceived and expected healthcare professionals to focus more on meeting the physical needs of patients in an acute outpatient setting such as a chemotherapy day care unit.

2.5.5 Financial support

This paper by Chapple et al (2004) focuses on individuals with lung cancer and their experiences of financial struggle and accessing benefits. Only one of the participants was from a different ethnic group. However, it is suggested that people from different ethnic and cultural backgrounds may have additional problems accessing financial assistance. Participants were not always aware of what they were entitled to regarding financial assistance. People with terminal cancer and

unlikely to survive for more than six months are eligible for financial benefits that can be accessed without delay providing the appropriate claim form has been completed by the doctor. The findings of this research suggest numerous barriers exist that prevent, prolong, frustrate and exhaust individuals during the process of applying for financial assistance.

Patients were sometimes reluctant to claim for financial support because of the stigma associated with the idea of asking for 'handouts' despite being seriously ill and having worked all their adult lives. The need to provide justification other than their illness such as viewing the claim in terms of a replacement for their old age pension was one strategy employed to overcome the stigma. Participants were not always prepared to admit that they had cancer because of stigma associated with the disease, which made them feel ashamed and unable to claim for benefits that they needed.

Barriers existed because of the illness and everything associated with it. For example people were dealing with their illness, being in hospital, having surgery, and struggling with vast amounts of information. Finances were, therefore, not considered a priority during the initial stages of the illness because participants were unable to recognize their potential future needs at critical moments in time. The crucial factor here was that financial benefits could not be backdated, which meant a probable financial deficit unless, claimed at the time of diagnosis. Thus if individuals were unable to claim or nobody claimed on their behalf, they may not have been in a position to claim until a later time when their financial status may have become critical.

Participants found the benefits system complicated, bureaucratic and confusing, stating that they needed professional advice from people who understood the process. They did not always have access to the appropriate person qualified to guide them through this process such as a benefits advisor, Macmillan nurse or social worker. There was confusion over what kind of financial benefits people were able to claim for and they relied on healthcare professionals to advise them. Participants were sometimes misinformed or did not receive the assistance they expected from hospital staff. Rejected claims resulted because the correct forms had not been completed. The process of claiming benefits took several months and

participants perceived the experience in terms of a 'battle' or 'tussle' getting acknowledged regarding legitimacy of their claims and dealing with people from the Department of Health and Social Security (DHSS) who were considered unhelpful. The participants who reported positive experiences had access to a Macmillan nurse or a doctor (GP) who initiated the process and was able to provide appropriate assistance at the time of diagnosis. Support groups were found to be especially accommodating inviting speakers from benefit agencies who provided professional guidance on how to access financial benefits. The sudden loss of income and struggling to gain financial benefits had a significant impact on patients and families in the present research.

2.5.6 Prioritisation of support

The authors of this final paper (Murray et al (2002) hypothesized that prioritisation of support services existed which were determined through the specific disease an individual had regardless of their own particular needs or requirements. The aim of this research was to explore two different illness trajectories in relation to patients' needs and access to support services. The participants (n=40) had inoperable lung cancer (n=20) or advanced cardiac failure (n=20). Carers and key healthcare professionals also participated in the research. The rising incidence and higher mortality of cardiac failure when compared with most cancers provided the rationale underpinning the selection of a non-malignant disease versus a common and terminal cancer.

The participants with lung cancer often experienced a vague onset of the disease and perceived a delayed diagnosis. The illness had a distinct terminal phase and the patients were able to plan for their demise. Participants with cardiac failure experienced a chronic progressive illness, episodes of acute exacerbation, no distinct terminal phase and often an abrupt or unexpected demise. Patients with lung cancer appeared to have some understanding of their disease and prognosis. There was however an apparent reluctance to discuss death and dying by some of the participants from each group (patients, carers and professionals). The cancer patients appeared to have greater access to printed information and had an understanding of their disease. Patients with cardiac failure did not indicate a clear understanding of their

illness and did not appear to receive information pertaining specifically to their disease in written form. Lack of knowledge or understanding was explained in terms of participants' inability to associate some of their symptoms with their cardiac problems; for example breathlessness. Prognosis was not usually discussed with participants who had cardiac failure. The professionals indicated a desire to inform the patients about their illness on one hand, while on the other to safeguard them from the reality of acute and sudden death.

Most of the participants had no input in decision-making regarding treatment choices which may be a reflection of their shortened projected survival time. Unlike patients with haematological malignancies they were not undergoing cancer treatment throughout prolonged periods, thus gaining knowledge, experience and expertise. The patients with lung cancer and cardiac failure asserted that the professionals knew best because they were the experts. It was generally understood that the healthcare professionals made the decisions and individuals accepted their recommendations without question. Side effects from chemotherapy often made patients with lung cancer feel worse than the symptoms from the actual disease. Treatment for cardiac failure was deemed as improving symptoms associated with the condition.

In relation to lung cancer, the prospect of death was a constant and real threat. The participants struggled to maintain some semblance of hope and were described as battling to maintain balance between optimism and despondency. In contrast, living with cardiac failure was perceived as a chronic incurable disease, which potentially could worsen. Therefore the prospect of death was not a constant threat to these individuals. Cardiac failure did not appear to dominate the patients' lives because of the presence of comorbidities. Patients and their carers implied they felt isolated and struggled with escalating disability and handling complex medications that were constantly changing.

Patients with lung cancer appeared to have access to numerous services available including assistance and information from cancer charities and other organisations. These services usually included access to a lung specialist cancer nurse during treatment. Very few of the cardiac patients had access to a cardiac nurse specialist. Similar findings are addressed previously regarding

prioritisation of support (2.5.2).

Services such as palliative care assessment, day care, help in the home, assistance with mobility and benefits advice were normally offered to patients with lung cancer and not usually to the patients with cardiac failure. These patients (cardiac patients) experienced lack of support and continuity from both the hospital and community. The GPs who participated in the research appeared to struggle acknowledging that there were inequalities relating to the type of help available for their patients. Perceived gaps in the service identified by cancer patients were difficulties experienced regarding parking vehicles at the hospital for example. Furthermore they suggested a need for emotional support at times when they felt particularly vulnerable such as waiting for news of laboratory test results or not knowing if treatment was feasible. Healthcare professionals, carers and patients did not always understand other people's roles (professional and voluntary), which was fundamental when accessing support for families and also evident in the present research.

2.6 Summary

The above synthesis should be considered in conjunction with the grid (Appendix 4) and the second and third order interpretations (Appendix 5). The above studies were selected according to the topic and relevance to the findings presented in this thesis; the research design (qualitative) reflecting the participants' experiences; patients and families living with cancer or chronic disease, and studies that reflected the healthcare professional's perspective. The synthesis is a reflection of the range of literature in view of the research findings. Therefore the above papers provide a retrospective review and supporting background knowledge relevant to the research and the generation of grounded theory presented in this thesis. *Contention* (battle, struggle, disruption and disharmony) emerges throughout the literature above, for example waiting for news of laboratory tests and not knowing whether or not treatment is still a viable option. The next chapter delineates the method used to undertake the research itself.

Chapter 3. Research methodology

3.1 Introduction

This chapter provides a detailed account of the research process from initiation to completion. The approach to the research incorporates the methods employed and difficulties encountered. A representation of the evolving research process is shown in Figure 2 providing an overview of mandatory administrative procedures, planning, organising and implementing of the project starting with the inspiration for the research study and ending with the writing of this thesis. Local Research Ethics Committee approval for the project was obtained in August 2005 as by this time fellowship funding had been obtained but a university place was not yet secured. It was important that the research project was established within six months of receiving the funding in April and commencing study at the university in early October 2005. Correspondence concerning the application for ethical approval can be seen in Appendix 6.

Firstly the study site, population and sample are introduced followed by sampling strategies, access, research design, data collection, data analysis, trustworthiness, methodological issues, management of the project, completed data collection, an introduction to the main category groups that emerged from the data and personal reflections on the process.

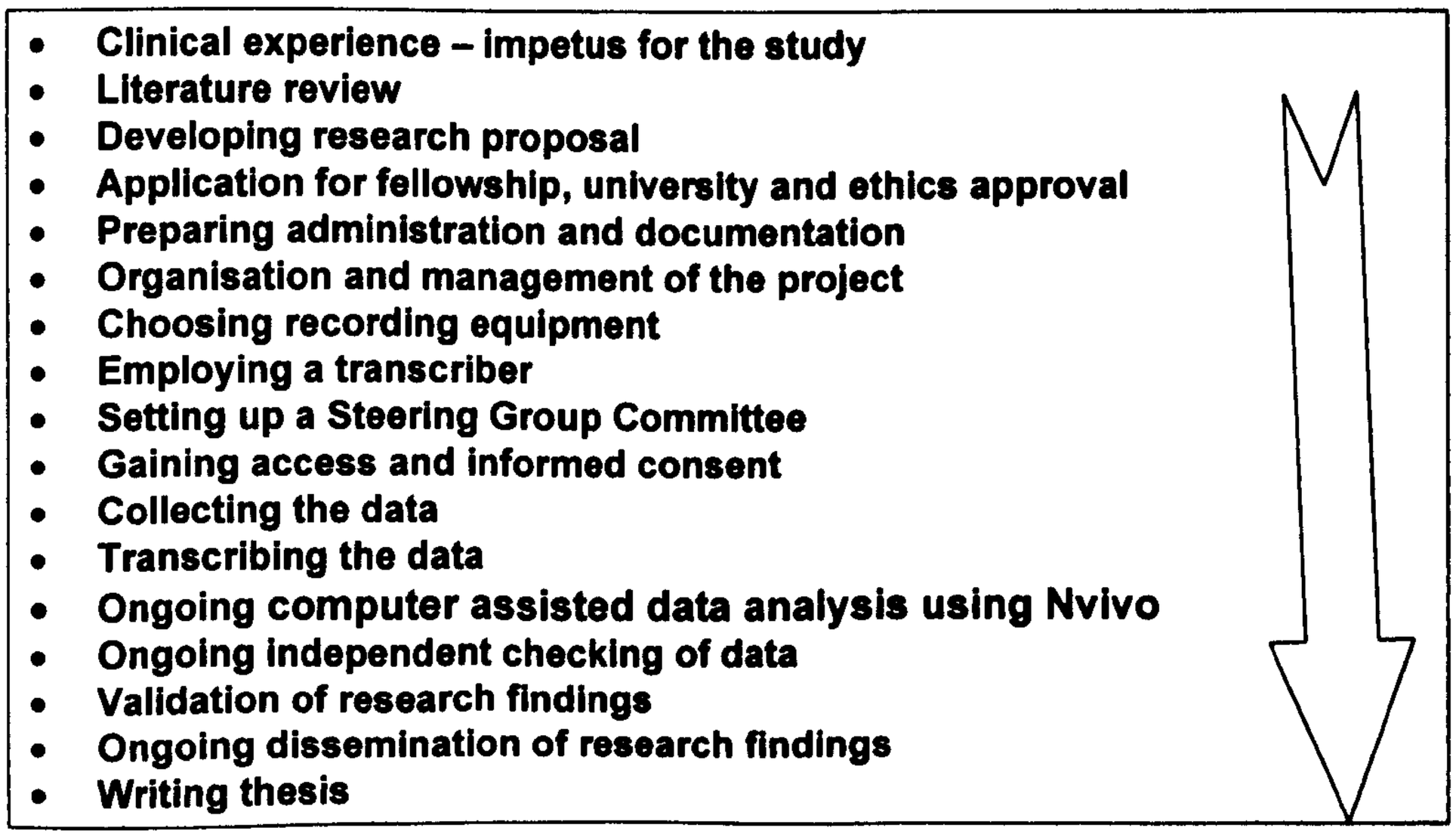


Figure 2 An outline of the evolving grounded theory research process

3.2 The study site

Patients (n=17) and family members (n=11) were recruited from a London NHS Trust (North East London region). The patients were treated regularly at the Chemotherapy Day Unit or were being monitored between treatments and seen by the Haematologists when attending the hospital outpatient clinic. Interviews were held in a quiet and private room either at the hospital, university or the participant's home. The study had been previously discussed with the relevant nursing and medical staff and permission for access was obtained prior to commencement of the project.

3.3 Population and sample

At the beginning of the research process it was necessary to state an approximate recruitment figure when completing application forms for ethical approval and funding. This proved difficult because an exact sample size in qualitative grounded theory research is determined at the time of theoretical saturation (which means no new data can add to the emerging theory; thus all avenues of exploration have been exhausted). To determine a set number therefore at a time when data collection has not yet begun is virtually impossible. The figure of 20-30 participants is documented as typical by researchers until saturation is reached using two or three interviews per person (Creswell, 1998, Morse, 2000). When applying for funding and ethical approval I stated that it was my intention to recruit approximately 50 participants. This decision was based upon my working experience and knowledge of dealing with Local Research Ethics Committees and the trepidation of rejection. The following reflective memo highlighted concerns associated with potential bias towards significant recruitment numbers and quantitative research:

Reflective memo.
Date: Friday 28 October 2005.
Before the lecture on grounded theory started yesterday we talked about ethics committees and the fact that there had been a number of qualitative proposals rejected. It's generally believed that committees are pedantic and biased towards quantitative research. They are not familiar with qualitative research and therefore lack understanding. In order to achieve goals a certain amount of 'creativity' may be required and it is an advantage to have had dealings with ethics committees in the past (having worked as a clinical trials coordinator).For example I stated approximately 50 patients will be recruited for the study. My

supervisor was clearly perturbed with this and I had to explain that I felt obliged to produce a 'number' on the application form to appease the committee members who (I believed) would not be familiar with the concept of theoretical saturation.

I data collection involved 46 interviews with three participant groups: p =17), family members (n=11) and healthcare professionals (n=12) addressed (3.6). Three couples (n=6) were interviewed twice. The following inclusion and exclusion criteria were based on the aims of the study, professional clinical knowledge and personal experience.

Inclusion criteria were as follows:

- Patients aged >18
- Patients with symptomatic, relapsed or refractory Multiple Myeloma (MM)
- Family member living with a relative who has MM
- Professional health care worker caring for patients with MM
- All would participate on a voluntary basis, and would have completed and signed an informed consent form.

Exclusion criteria:

- Patients with an estimated length of survival of less than three months
- Patients who were cognitively impaired.

Although the youngest patients I have known attending the chemotherapy day care unit were within the age range of 31-40 years, it is documented that others have been diagnosed with multiple myeloma in the younger age range of 17-22 years (Hewell and Alexanian 1976) and 21-23 years (Ishida and Dorfman 1995). Furthermore I was aware of younger patients at other hospitals in the UK through networking with nursing colleagues. One large NHS Trust hospital in the Midlands for instance currently had 6 patients under the age of 25 years. The age range criterion was therefore based upon the potential of including younger participants.

3.3.1 Purposive sampling

Purposive sampling in qualitative research involves the researcher making a judgement based on prior knowledge about the population in question (Polit and Hungler 1991) and was used in conjunction with a process of theoretical sampling. Purposive sampling was employed initially whereby patients were

selected according to age ranges, trajectory of illness, people living alone, people living together (couples, family) and ethnicity. This was done with the intention of achieving maximum variation based on the assumption that different issues would arise at different stages of the illness or at different times of life. It was also assumed that key issues emerging from participants living alone would be different to those who had a spouse, partner or relative living with them.

The first 'patient' interviews (n=11) involved participants known to me from my clinical practice area. As the researcher, this meant that I was an integral part of the area under investigation and was aware that the relationship established with the patients and families had to be acknowledged. However, it could be argued that having an established relationship with participants and being known in the clinical area not only facilitated access and recruitment, it also provided an opportunity for individuals to discuss issues that were significant to them. Some of these issues seemed to me, to be disclosed for the first time and many appeared to view the interview experience as cathartic. However I was aware that as part of the establishment (and known to the participants) there was a possibility that I could influence the research process; (this issue is addressed subsequently in the section on methodological issues).

Ethnicity was not considered overtly at the start (with the exception of one patient originally from America), the first few patients interviewed (n=11) were white British. This group of patients was a reflection of the population that attended the hospital. However recognising that approximately half of the general 'myeloma' population were of Afro-Caribbean origin I did not feel justified in undertaking this project and excluding this ethnic group. Purposive sampling was employed therefore to extend the ethnic profile of the patient participant group. Eventually this included 5 Afro-Caribbeans and 1 West African; all of whom were introduced by the consultant haematologists or nursing colleagues via the outpatient clinics. Features of the purposive sampling framework included:

- Age ranges, illness trajectory, ethnicity
- 31-40 (1 couple)

- 41-50 (2 couples, 2 singles)
- 51-60 (1 couple, 3 singles)
- 61-70 (3 couples, 4 singles)
- 71-80 (1 single)
- Diagnosed 3 months, 1,2,3,4,5,6,9,14, and18 years.

3.3.2 Theoretical sampling

In a grounded theory approach theoretical sampling is utilized which means th t data is collected, coded, analysed and used as guidance for the next da.a collection phase; thus ongoing decisions are based on previous data collected. The data collected from the first group of patients interviewed (n=8) in this study, for example, had been used to guide the second and ongoing group of participants. This was repeated so that following each data collection further decisions regarding selection of participants, sample size, and type of data to be collected were based on emerging findings (Glaser, 1978).

Coyne (1997) makes a useful distinction between purposive and theoretical sampling and attempts to clarify some of the common misinterpretations in the literature. Purposive sampling, Coyne suggests, involves selecting the sample at the beginning of the study based on what is known about the area under investigation. Therefore it is a decision guided by previous clinical experience. Theoretical sampling is not guided by previously conceived notions or prior experience. Instead, theoretical sampling is guided by data that have been collected and analysed. The confusion between both terms arises when theoretical sampling becomes purposive; for example when a sample is selected according to emerging and developing categories in the data. Coyne argues that purposive sampling is not always theoretical and suggests renaming or replacing the term '*theoretical sampling*' with "analysis driven purposive sampling" (Coyne 1997:11).

3.4 Gaining access

Letters of invitation including participant information sheets, GP letters (informing the patient's GP) and consent forms were prepared for three participatory groups (patients, family members, and healthcare professionals). Examples are shown in Appendix 7. An invitation to participate letter (participant

information sheet) was originally prepared with the intention of making numerous copies and leaving them with the consultants to hand to patients when they attended for outpatient clinic appointments. This would enable the patients to read and digest the information at home allowing adequate time to consider whether or not they wished to participate in the study. The patients then had the option of contacting me (the researcher) if and when they chose to do so. Alternatively the consultant could inform me as to whether I could contact the patient directly having sought their consent to do so. This was not applicable for the first batch of interviews; as stated previously, these participants were known to me from my clinical area of practice. I had discussed my plans for leaving the clinical area and becoming a full time student with the idea of undertaking my own research project. All the patients I had spoken to showed an interest in the study and a desire to participate. As a result I was given additional contact details such as e mail addresses and mobile telephone numbers encouraging me to contact them in due course.

Having not had any form of contact with individual patients for several months, the approach adopted was to write a letter reminding them about the research (example shown in Appendix 8) enclosing the additional information sheet and consent form. However, there was always the concern that these patients could deteriorate suddenly. Away from the clinical area I was not aware of the day-to-day developments when individuals' conditions change dramatically over a short period of time. Patients were sometimes admitted to other hospitals; others may have been due for routine clinic appointments; or expected to attend as outpatients for chemotherapy, blood products and platelet transfusions, or radiotherapy.

Being a Trust employee I also retained access to clinical documentation on the Electronic Patient Records (EPR) computerized system within the hospital closely situated to the university where I was based. The proximity was useful as I was able to continue to liaise with consultants and nursing colleagues if I required further information prior to contact. It was viewed as advantageous having 'inside knowledge' of how an organization functions on a day-to-day basis and knowing where to find people on a particular day. Having colleagues

who were supportive and being in a position where I was known to the department also facilitated my access as a researcher. I was known as a hospital 'research nurse' and despite the fact that I became a full time university student, I suspected that I was viewed by my colleagues 'in the same light'. They were, however, aware that I was involved in a nursing as opposed to a medical (clinical trials) study. This meant that there were few barriers and my presence in the clinical area was never questioned. Not having to spend time negotiating access and getting to know staff certainly proved beneficial.

3.5 Research design

The design employed in this research was grounded theory. Grounded Theory was developed by Glaser and Strauss in the 1960's while they were undertaking a study of the experiences of dying patients. Glaser stressed that Grounded Theory was, in fact, 'discovered' and not 'invented' (Glaser 1998). It was a general methodology that could accommodate either quantitative or qualitative data, the latter being the most popular, (Glaser and Holton, 2004). Both two sociologists came from different philosophical and research backgrounds, which eventually led to the further development of separate methodological approaches. Some of the techniques and procedures that were later developed by Strauss and Corbin (1998) were also used as guidance in this research. However, Glaser's unrelenting pursuit for 'staying open' to that which was emerging from the data has had a far greater influence on the direction of this project.

Grounded Theory is primarily used for exploring a relatively unknown phenomenon such as living with multiple myeloma. Qualitative approaches are used to discover the meaning of lived experiences. These approaches provide the depth, and richness of data not acquired through quantitative measures. The central feature of grounded theory methodology that differentiates it from other qualitative approaches is the aim of theory development. Theory is defined as a group of well developed categories, themes or concepts which are systematically interrelated to form a theoretical framework with evolving statements of relationships explaining the meaning or the consequences of the phenomenon or event, (Strauss & Corbin 1998). The research findings are

summarised within a framework of integrated conceptual hypotheses (Appendix 9). A quote by Gummesson (2002:132) sums Grounded Theory up succinctly: "*Take the elevator from the ground floor of raw substantive data and description to the penthouse of conceptualisation and general theory*".

The chosen design (grounded theory) is used where areas of limited research and insufficient knowledge has been identified. This methodology not only provides the best fit for the research question or statement, it is also structured, comprehensible, and easy to work with. A further appealing quality is that it is a general inductive approach that can draw on any theoretical perspective although the majority of grounded theory studies in nursing tend to utilise the sociological symbolic interactionism stance. The decision to draw from a particular theoretical perspective for this study was later determined following identification of the core category named *contention*.

3.6 Data Collection

A pilot study was undertaken with a small convenience sample at the time of writing the research proposal in March 2004. A total of five semi-structured recorded interviews were undertaken to assess the feasibility of the proposed study. The original interview schedule developed from the cancer literature is shown in Appendix 10. The aim was to find out what the key issues were that patients discussed and whether or not they coincided with my expectations and assumptions drawn from my clinical practice. I interviewed two male patients and their wives, and a single male patient who was estranged from his wife. The couples were interviewed in their homes while the individual was interviewed on a hospital ward where he had a single room. The couples were interviewed separately although the second couple remained together in the same room so were able to listen to each other's interview. The following extracts are taken from an early process memo discussing the justification for undertaking the pilot study and valuable lessons learned from it.

Process memo
First interview and the new digital voice recorder
Date: 29 March 2004
The first interviews were held in a private London flat away from the hospital

environment. There are sound arguments for running a pilot and one of the practical implications that came to light included running out of recording time during the second interview with the patient's wife which I had not anticipated with the new 90 minute digital recorder recently purchased. One of the main advantages of the recorder I believe is the size which is extremely small and unobtrusive. Previously while studying for an MSc and interviewing nurses the tape recorder was larger and appeared to have a significant impact on the way the interviewee behaved. Some nurses would talk freely and suddenly slow down during the interview stare at the recorder and appeared to deliberate or reconsider what they were about to say or how they were about to say it. Others stated that they felt uneasy because of the recorder and although they wanted to participate in the study they found it difficult to speak despite time spent establishing a rapport and reassurance of anonymity and confidentiality.

The difference with interviewing a patient living with a haematological malignancy was that he really wanted and needed to talk and although he was aware of the recorder he did not appear to be threatened by its presence. When he had finished speaking he picked up the small digital recorder and wanted to check it was all there by playing it back and listening. I had planned on an unstructured approach but this proved difficult. Having known the patient for several months I was confident that he would be able to discuss issues that were important to him. His own words were "You must tell me exactly what you want". This is a clear case of 'déjà vu' and learning from previous interviewing experience where a focus and semi-structured techniques are best employed to reflect the aim of the study and avoid huge amounts of data that do not serve any useful purpose.

A disadvantage which became apparent immediately following these interviews regarding the use of the new digital recorder was that I had no means of a backup system. With a conventional recorder there are tapes which can be stored safely and locked away. A maximum of 100 files can be used in Folder A and B on the small digital voice recorder which could get lost or misplaced resulting in the potential breach of confidentiality and loss of huge amounts of data. The best option is to download onto a computer for storage and unfortunately my out of date Microsoft Works Windows 95 does not enable me to do this. Therefore the only option I have at present is to transcribe the interviews in full and erase them.

In conclusion the main operational issues here to address are as follows:

- *Planning and Preparation*
- *Timing of interviews*
- *Compatibility of new technological equipment*
- *Safety and storage of data*
- *Provision of a backup system*
- *Identifying and listing new equipment required for the study*

Four of the above interviews were transcribed verbatim. I was disappointed with

the general quality of the new recorder and it was not possible to transcribe the final one (the patient I interviewed on the hospital ward). This man spoke quietly and quickly. The background noise that the recorder picked up was overbearing. The location and timing was not very good either as the nurses were coming and going through swing doors that were banging constantly. Meals were on their way and staff were standing and talking just by the room door in the corridor outside. Two or three people entered the room while the recorder was on. It was not possible to salvage any of the conversation even with the help of a transcriber who later attempted to assist me with the task.

The main data collection commenced in January 2006 using a semi-structured format and recorded interviews. Semi-structured or focused interviews help to ensure that specific topics relating to the aims and objectives of the project will be covered. This approach also allows ample flexibility in scope and depth (Polit and Hungler 1991). Recorded interviews provide direct evidence of human experiences relating to the phenomenon and determines their accuracy. There has to be a sufficient period of time between interviews to allow for full verbatim transcription of the recorded interview and analysis to be completed in order to guide further data collection. The proposed interview topic guide shown in Appendix 11 gradually evolved into more specific questions based on key issues emerging (Appendix 12). A follow up interview of the first couple I originally interviewed (P 001.F 002) in March 2004 was undertaken. This was done because a period of almost 2 years had elapsed and I thought it would be interesting to see how they were getting on with their lives and what changes may have occurred over the period of time. The second couple (P 027, F 028) were also interviewed again three years later in June 2007. The single man I interviewed sadly died (aged 48 years old).

In addition to the main data collection demographic data was gathered from the patients and the healthcare professionals participating in the research (Appendix 13). Patient sample characteristics included occupation, date of diagnosis, classification of myeloma and family status. The healthcare professionals sample characteristics provided information relating to their professional status and length of service. This additional collection of

demographic variables aimed to provide an overall picture of the sample characteristics (Burns and Grove 1997). Background information may also be important in understanding participants' responses and attitudes (May 1991). It was anticipated that some of the interviewees would welcome the opportunity to talk while others found the physical and emotional impact of the interview exhausting.

The following process memo highlights the emotional impact on a patient's wife, who was a retired nurse, and had always appeared cheerful, attentive, and in control:

Process memo
First interview
Date: 29 March 2004
Two separate interviews were held one of which was with the patient and the other was with his wife. Each person left the room while the other was interviewed. I hadn't anticipated the emotional impact this had on the patient's wife and her need to talk to someone which was not only extremely fundamental but provided an insight into each of their perceptions of the illness and the impact this had on their lives and that of their family and friends.

It is vital for researchers to stay vigilant and sensitive to sudden alterations in mood and be prepared to provide support during and following an interview. I was able to utilize my interpersonal and specialist nursing skills when needed. It is suggested that the development of the nurse and patient relationship is an important factor influencing the provision of supportive emotional care (Skilbeck and Payne 2003) hence the importance of spending adequate time establishing a rapport with unknown participants prior to commencing the interview. At each interview I carried a folder with contact details of The Cancer Counselling Trust, Myeloma UK help line, and CancerBACUP, which were readily available so interviewees could access additional ongoing support if required.

3.7 Data analysis

In grounded theory data analysis involves a process of continuous interplay between the collection of data, analysis, and the writing of memos throughout the research process (Strauss 1987, Strauss and Corbin 1998). The approach to data analysis in this study was guided by procedures suggested by Strauss

and Corbin (1998) which follow:

Stage 1. Listening to and transcribing recorded interviews
Stage 2. Detailed line by line analysis and naming concepts
Stage 3. Organisation and category grouping of named concepts and writing memos
Stage 4. Establishing chronological order of named categories and subcategories
Stage 5. Immersion into data and searching for repeated patterns of events
Stage 6. Asking questions and making comparisons
Stage 7. Making amendments to interview schedule based on emerging concepts
Stage 8. Identifying the core category
Stage 9. Validation from participants.

3.7.1 Heading in many directions

From the beginning of this research the emphasis was on what is happening and what is going on in the data. The naming of concepts, or coding, was assisted with the use of Nvivo version 2.0 qualitative software. This is discussed in more detail below (3.11). Open coding is intended to lead the way showing the direction in which to take the research which continued by means of theoretical sampling (when the researcher becomes more focused on a particular problem or issue). As mentioned above theoretical sampling is the process of collecting, coding and analysing data before deciding what data to collect at the next interview; thus the process of data collection is determined by the emerging theory (Glaser and Holton 2004). An example from a transcript and an illustration of how the methodology works using various levels of coding and corresponding theoretical memos is shown in 3.7.5.

One problem with purposive sampling, with the aim of maximising variation, is that the researcher ends up managing vast amounts of data and is in danger of heading off in many directions. However, making comparisons and searching for patterns may help to identify key issues. For example if two or more participants discussed a similar issue spontaneously, this was explored further with others. Organising codes into categories proved complicated especially when one code could be placed under several category group headings for example *bone pain* as a named concept (code) had connections with several categories such as physiological impact, communication, and psychosocial impact depending on the context and interpretation of meaning in the data. There was no obvious sequence or chronological order for example as

mentioned in stage 4 as the process sometimes seemed chaotic and overwhelming.

3.7.2 Writing 'memos'

The writing of memos began at the start of the project and were used in this research to document reflective thoughts, ideas, and concerns such as process operational and theoretical notes recorded throughout the process. An operational note is defined as "memos containing procedural directions and reminders" (Strauss and Corbin 1998:217). Theoretical notes are analytical thoughts and ideas about theoretical sampling and other issues. Diagrams were also used to illustrate relationships among concepts (example shown in 3.14). The writing of theoretical memos hold centre stage in the process of generating theory; it is intended to assist in elevating data to conceptual level and generates the formation of hypotheses between the categories and concepts at dimensional and property levels (Glaser and Holton 2004).

3.7.3 Returning transcripts for clarification

Transcripts were also returned to participants for clarification of meaning and to make sure that there were no errors or misunderstanding. Forbat and Henderson (2005) address the potential ethical implications of returning transcripts by mail, which could result in a breach of confidentiality if delivered to the wrong person in error. It is also argued that it may not be appropriate to return transcripts to participants especially if revisiting sensitive material, which may be upsetting. Alternatively participants may not have given consent for any further contact or follow up (Forbat and Henderson 2005).

Duffy (2004) highlights practical issues in relation to transcription errors and maintains that it is vital to check and recheck prior to analysis and not to assume that the transcriptions are correct (regardless of the fact that the researcher may have employed a reliable transcriber). The transcriber employed for this research was an experienced medical secretary which was helpful regarding general medical terminology. However, it was also necessary to prepare a glossary of terms used in haematological oncology including a list of common medications as the transcriber was from another specialist medical

field (thrombosis research) and thus was unfamiliar with some of the language used by the participants. The odd word can be missed out completely and therefore alter the meaning, or words can sound the same. For example pear and pair or I and eye or nose and knows. Other difficulties that may arise include accents, colloquialisms and the speed at which participants speak.

3.7.4 Amendments

Making amendments to the interview schedule continued throughout the research process and were determined by the emerging concepts derived from data collection at previous interviews. The first batch of patient interviews (n=8) commenced with a semi-structured approach opening with the question of "What's it like living with multiple myeloma"? My concern about an unstructured approach was that a participant might not know where to start or might not understand what the researcher is asking. On the other hand it would allow the participant to talk freely so that there was no restriction on the amount and type of data collected. The prepared topic guide referred to previously (3.6) proved to be very useful. This focused on the aims and objectives of the study and also allowed the participants to tell their story. It was important to try and approach the research with no preconceptions and allow the participants to discuss the key issues that they felt were most relevant. The working example that follows highlights a key concern 'delay in diagnosis' and the impact this had on the individual:

3.7.5 The working example

The following working example involves one of 25 original categories introduced (3.14) 'diagnosis' and one subcategory called 'delay in diagnosis'. Other 'provisional' subcategories included for example, 'shock of diagnosis' and 'communication'. The category, subcategory, coding with extracts of selected data, and corresponding theoretical memos are shown with the aim of demonstrating how the methodology works.

The GPs involved in the following extracts were approached by a nursing colleague known to me and to the doctors (Locality Deputy Team Manager). My nursing colleague informed me that the GPs (n=3) were interested in

participating in the study. They were given letters and information about the study. Following that we communicated by e mail and arrangements were made to meet for interviews.

- *Category* – Diagnosis:
- *Subcategory*: Delay in diagnosis
- *Open code* (named concept): Repeated visits to the GP
- *Axial codes* (link between category and subcategory): Rarity of disease, non-specific onset
- *Theoretical code* (conceptual code explaining context, cause or consequence): Diagnostic constraints

Patient transcript (Purposive sampling)	**Code:**
*014: "I'm just not getting any better - **back to the GP, back to the GP, back to the GP**. Finally, after, several months of this and it just wasn't getting any better, I said to the GP, I'd gone over to Canada and my dad said get an MRI (*Magnetic Resonance Imaging) scan *done, I came back and said to the GP I want an MRI done, just to see what the heck this is and he said yes but you're 'gonna' have to wait six months, and I said I can't wait six months, 'coz' I was almost bent double at that point, I could barely get to the GP's office, I could barely get anywhere, and it was just absolute agony. I couldn't sleep, I was just in constant pain. So I said give me a list of names of all the bone specialists so I'll go private and go try find out what this is, since you don't know but I understand It's, **it's rare to see**, it's hard to diagnose myeloma in the first place and it's also rare to see it in a youngish chap so they probably wasn't looking for it. But the fact that the specialist just looked at the bloods and went with calcium levels this high, what else would you think? So I was disappointed, that the disease had been allowed to progress to the state*	Repeated visits to GP Rarity of disease

that it had, where I was, well I think, pretty nearly gone before I had to do something, to find out what was wrong and if I hadn't, then that would have been it, and as it, as it happens, I've had off and on 4 good years and I might not have had those. So cross, a little bit cross" …	

Theoretical Memo:
Date: 5 September 2006
Delay in diagnosis and repeated visits to the GP have appeared a number of times and seem to be a common pattern emerging from data collected so far. Is this because the disease is uncommon and GPs do not expect to see it? Why is it difficult to diagnose? More importantly why does it apparently take so long for any investigation to occur? This is something that is worth exploring further. A common presentation is backache and I wonder how many patients are seen in the GP's surgery with this complaint and how many differential diagnoses if any are considered and at what stage?

GP Transcript (Theoretical sampling)	**Code:**
*026: "It is difficult because my understanding of some of the main symptoms you know, well backache being the obvious one, is such a common symptom, which we see everyday really without exception. I think the pointers are, may, correct me if I'm wrong, but the position of the backache, it's a little bit of an atypical backache, I think that these folk describe to us, thoracic upper backache rather than, if you like, a 'bread and butter' backache, which is lower back pain but some of the other associated symptoms as well, they're **often non specific** I think if there's say an **abnormal presentation**, so if there's a strong **family history of cancers**, or a **strong history of cancers**, say the patient had prostate cancer, or had breast cancer and you were thinking of a secondary deposit, you might do an X-ray at that stage. If the symptoms were very severe, so if it, if a sort of simple analgesia or normal analgesia wasn't helping, then*	Non-specific onset Abnormal presentation Risk factors

you'd do an X-ray. If they've had failed treatment, so if they say that they'd been to a physiotherapist on their own for six months or a year and that hasn't helped, you'd do it then. So if it's like I started having back pain sort of two weeks ago and it's not getting any better doctor and it goes down my left leg or whatever, then we wouldn't necessarily X-ray at that stage but say go an see a physiotherapist and have that for, I mean they'd have to wait a few months to see them and then it's three or four … and then a couple of months on the physiotherapy and then an X-ray, if it doesn't improve. So there are certain circumstances where we would X-ray early, if we we're concerned".	

Theoretical memo
Date: 4 April 2007

Both of these GP surgeries are in Essex which is one of our main referral areas. Each has one patient with multiple myeloma. One GP told me that out of a total of 2,300 patients assigned to him there is one lady diagnosed with multiple myeloma. He mentioned a second patient with paraproteinaemia but couldn't say if this was MGUS or a smouldering myeloma. The data collected suggests that the disease is difficult to diagnose because of its rarity and its non-specific onset. There is the assumption that backache is often seen as something common such as muscular strain and analgesics are prescribed. Failing this a stronger or different analgesia is given or a referral to the physiotherapist which can take months. If the presentation is considered uncommon, abnormal, severe, or there is a family history of cancer it is investigated immediately. The policy regarding backache is to treat the symptoms and not investigate the cause until much further down the line when the disease has been allowed to progress. I suggest this is one of the major factors influencing the delay in diagnosis. A delay in diagnosis ultimately means a delay in treatment. The lingering question is what difference does this delay make to the patient who has an incurable disease like multiple myeloma? Firstly as shown in the patient's extract above it has a huge emotional and psychological impact on the individual involved and possibly results in a loss of faith in the GP. Secondly patients with lytic bone lesions can be treated with medication, whereas if bone fractures have developed, these require surgical intervention. Someone with advanced bone disease is going to have a poor quality of life and may be confined to a wheel chair unable to walk. The impact on prognosis is highly significant in a patient with multiple vertebral fractures, unable to ventilate their lungs properly, and at risk of severe chest infections because it reduces their

chances of survival further as any aggressive form of treatment such as high dose melphalan will be considered too toxic.

3.7.6 Identifying the core category

The core category is the emerging central concept that relates to all the main categories and appears frequently throughout the transcripts. Identifying the core category was a true 'eureka' moment and although struggle represented a common pattern there were other strong interrelating concepts such as 'battle' or 'fight', 'disruption' and 'disharmony'. *Contention* appeared to encompass all four interrelating concepts and in order to develop some understanding and definition, a concept analysis of *Contention* was undertaken (5.3). The concept analysis involved exploring relationships between concepts by defining their attributes. The defining attributes associated with *Contention* for example include struggle, battle, disruption and disharmony. The aim was to describe and examine this concept and determine whether or not it was associated with other words in order to verify its actual and potential utility with regard to its meaning (Walker and Avant 2005). The concept analysis was undertaken using the framework suggested by Walker and Avant (2005) which included identification of all uses of the concept *Contention,* followed by constructing a model case; borderline, related, contrary, invented and illegitimate cases; identification of antecedents, consequences and definition of empirical referents. An articulation of the rudiments of the theory of C*ontention* is presented in Appendix 14.

3.7.7 Validation

Validation from participants in stage 9 involved selecting a small number of interviewees (n=8) and asking them to look at the conclusions, the core category and theory that was developed from it. An example of an e-mail communication follows:

Following your assistance with the validation of research findings when you kindly gave me examples of struggle, battle, disruption and disharmony. Can you now look at the following list and tell me if any apply to you or have applied to you in the past and if so give me an example? Or tell me if you can identify with any of the following and in what way?

- *Communication issues or problems*
- *Communicating bad news in a good way or in a bad way*
- *Using complex terminology*
- *Living with uncertainty*
- *Perceptions of the illness (others' reactions towards you and your illness)*
- *Novice to expert patient (inexperienced patient to experienced and knowledgeable)*
- *Disrupted life*
- *Physical impact of disease*
- *Emotional impact of treatment*
- *Physical impact* of treatment
- *Social/economical impact of disease*
- *Support needs*
- *Sexuality*
- *Invisible struggle*
- *Impact of policy makers/legislation*
- *Decision-making.*

Although participants provided feedback before in relation to the accuracy of the transcripts this provided a final validation of the outcome of the study. Participants who saw the theory generated from this research were able to recognize it and provided narratives as evidence of this (Appendix 15). This not only provided a test for factual and interpretative accuracy but also enhanced the credibility of the study which is discussed next in section (3.8).

3.8 Trustworthiness of the study

Credibility, fittingness, auditability and confirmability are the terms used in qualitative research in meeting tests of validity and reliability (Lincoln and Guba 1985). However, Glaser argues that grounded theory is intended to be a rigorous and trustworthy methodology (Glaser 1998) and postulates inappropriate application of traditional quantitative principles used extensively in qualitative data analysis (Glaser and Holton 2004).

The relationship between the different terms for both qualitative and quantitative research approaches are clarified here. Credibility or internal validity as it is known in quantitative research is concerned with truth and lack of distortion. Completed transcriptions are returned where possible to the participants for clarification of meaning and to allow necessary amendments. Not all participants agreed to have their transcripts returned and two patients died

before I was able to return the completed transcriptions. Fittingness (external validity) determines whether the study findings have applicability in other areas or with other participants, (Lincoln and Guba 1985).

Auditability, commonly known as reliability in quantitative research, concerns consistency which determines the extent to which a study can be replicated. Thus it is assumed that a different researcher will obtain similar results or theoretical explanations by following the same research procedures. It can be argued that exact replication concerning human behaviour or unique circumstances is not possible regardless of what procedures or methods are employed (LeCompte and Goetz 1982). Consistency can also be established through the utilisation of peer member checking or collaborating with another researcher in order to independently check the data. The individual who assisted me in this research was a qualified counsellor and lecturer practitioner in palliative care. A transcript was viewed in advance and a meeting was then arranged to discuss key issues emerging; agreement was reached regarding named concepts.

Confirmability or objectivity is the criterion for judging the trustworthiness of the study and for this to be established credibility, fittingness and auditability must all be accounted for, (Lincoln and Guba 1985). Credibility was established through validating the findings and theory generated in this grounded theory research which has been addressed previously (3.7.7).

Fittingness or applicability to other areas of health care and life might include chronic and progressive illnesses such as multiple sclerosis, trauma, acute surgical and medical events, childbirth and bereavement, moving home, business, political and financial change. Auditability, or consistency in order to replicate the study, was determined through the methodology of grounded theory and the decisions made throughout the process; all of which were documented and accessible. Confirmability therefore aims to establish that the findings are as accurate as possible having evolved directly from the participants and not from the biases or motivations of the researcher.

Trustworthiness and data checking were supported by:

- Transcription of interview data by an independent data transcriber, with accuracy checked by the researcher.
- Multiple sources of data analysis - hand analysis and computer assisted qualitative software analysis.
- Distribution of study findings to participants for validation.
- Working in collaboration with the academic supervisors, and peer member (independent) data checking
- A clear audit trail as per this written account.

3.9 Methodological issues

3.9.1 Emergence verses forcing debate

Glaser has written extensively about 'staying open' to the emerging research issues and not influencing or forcing the data in order to produce results that do not truly reflect the participants main concerns (Glaser 2005; Glaser and Holton 2004; Glaser 1998, 1992,1978; Glaser and Strauss 1967). Glaser (1992) criticises Strauss and Corbin's (1998,1990) highly structured and complex techniques involving preconceived questioning that could force alternative theoretical explanations at the risk of jeopardizing the true reflection of emerging theory.

Glaser maintains that entering the research field with preconceived ideas can undermine the process and leads to potential bias. In reality, however, it may not be possible to enter the field with no preconceived notions particularly when the researcher is a part of the area under investigation. Preconceptions associated with professional issues may also enhance understanding of what is going on in the data. Glaser and Strauss (1967:46) maintained that *theoretical sensitivity* is something that gradually develops with professional experience, is associated with an individual's personal qualities and is defined as: *"Ability to have theoretical insight into his area of research, combined with an ability to make something of his insights".*

However, there are contradictory opinions regarding whether the literature should be reviewed at the start of grounded theory research and continue throughout the entire process as an analytic tool aiming to identify links to existing theory (Strauss and Corbin 1998, 1990). Alternatively, to view the

literature towards the end of the process when the core category has emerged and constant comparisons can be made between the emerging theory and extant knowledge (Glaser 1998) is also advocated. The latter requires a postponement of viewing the literature and 'putting on hold' preconceptions prior to and during data collection. The objective is to allow the researcher freedom and openness to the emerging data and reduce assumptions regarding what the researcher 'thinks' might be found in the data. This does not however mean that the researcher should not read any material during the course of the research. Glaser (1998) stipulates that the reading of literature from other substantive areas may serve to enhance *theoretical sensitivity*.

In this research it was necessary to undertake a review of the cancer literature which provided background information on multiple myeloma and identified gaps in existing research (Creswell 1998). It also fulfilled a mandatory entrance criteria in application processes involving university placement, funding scheme, and ethical approval. This literature review was undertaken early in 2004 at the time of writing the research proposal. The main data collection did not commence until 2006 thus a substantial period of time had elapsed (although the lack of available literature suggests this would not have changed markedly).. There are also conflicting views concerning techniques and procedures that impose devices and frameworks intended to help stimulate analytical thoughts concerning development and integration of categories in grounded theory methodology (Strauss and Corbin 1998, 1990). The use of such frameworks according to Glaser (1978:117) is gratuitous and he argues against the researcher using a "*ready made outline*" in which to assist theoretical integration:

> *"No ready-made scheme works well if at all. He should simply start sorting the categories and properties in his memos by similarities, connections, and conceptual orderings. This forces patterns which become the outline"* (Glaser 1978:117).

3.9.2 Insider/practitioner researcher

An account of my professional role was previously introduced (1.3, 1.4) within the area under investigation. The advantage of being an insider/practitioner

researcher meant that my presence in the clinical area was immediately accepted. Therefore gaining access and rapport with the hospital staff was established prior to the study commencing which can be very advantageous and may save prolonged periods of time otherwise engaged with negotiations and seeking approval from the 'gatekeepers' who authorise access (Simmons 2007, Klein and Johnston 1979). Gaining access and establishing trusting relationships may be problematic for some healthcare professionals attempting to undertake research in establishments where they are not well known (Simmons 2007, Klein and Johnston 1979). It is suggested that the 'insider' researcher who has spent a significant period of time in the area under investigation has the advantage of having access to a broader and more in depth range of information (Hewitt-Taylor 2002) and support from managerial staff and colleagues (Simmons 2007). The counter argument to the 'insider' researcher is that the 'outsider' researcher is less likely to be influenced or biased and is more likely to maintain some semblance of objectivity (Allen 2004, Hewitt-Taylor 2002). The outsider/practitioner researcher, however, may feel disadvantaged because of the amount of time required in order to gain access and establish trusting relationships within an unfamiliar environment (Allen 2004).

Being known by many of the participants in this grounded theory research, however, may have influenced the way in which the data was collected, analysed and interpreted. This was addressed in numerous reflective and reflexive or 'self critique' field notes, peer reflection with independent data checking and memos aiming to acknowledge the potential for bias, maintain vigilance and strive to the notion of 'staying open' to the emerging theory (Glaser 2005, Allen 2004, Glaser 1998, Field and Morse 1985). Furthermore It is argued that '*theoretical sensitivity*' (Glaser and Strauss 1967) was enhanced having had prior knowledge and understanding of the impact of the illness, management of the cancer and familiarity of the specific haematological terminology which many of the participants in this current study used.

One advantage of knowing some participants was that I did not have to spend time establishing a rapport or gaining their trust. Allen (2004) argues that the

quality of data collected is determined through the strength of the relationship between researcher and participants in the field. I felt that most people knew me well enough to talk fairly freely and that they were confident to do so in a relaxed and informal environment. However there was the possibility of my influencing the participant while collecting data. For example I may have been perceived as part of the establishment (Allen 2004) and therefore the participant may at times have been a little wary or conservative with responses to certain questions regarding the healthcare system. How did I know whether or not they were simply saying what they thought I wanted to hear, or saying something to please me? Participants sometimes stated that they had no complaints and everyone (healthcare professionals) were wonderful. This type of response led me to believe that participants thought they were being asked to criticise their care and needed reassurance that this was not the case. Thus the dilemma of the dual role, practitioner-researcher identity can be particularly challenging (Allen 2004) for novice researchers. It is suggested that there may be less ambiguity or confusion associated with the dual role of practitioner/researcher if the investigator's professional status is not disclosed (Klein and Johnston 1979) when initially introduced.

The way in which questions or prompts were used during interviews made a significant difference regarding participants' responses. For example the question "can you talk to me about your recent stem cell transplant"? proved to be far more productive than "have you got any issues relating to the healthcare system"? The additional knowledge that I had about an individual may also have influenced data collection or my responses. The following example is taken from field notes demonstrating reflective thoughts, 'self' critique and constantly questioning the way in which the data was collected and analysed (Hewitt-Taylor 2002, Strauss and Corbin 1998, Field and Morse1985):

Field Notes 24 January 2007
P 023
The interview lasted for approximately one and a half hours and we sat and talked for several minutes following this. Dave seemed very relaxed throughout and I thought the interview went well. I think I have improved on picking up cues and not changing the course of the conversation. It also seemed easier for me as I know Dave especially in comparison to yesterday's interview when I met

Karen (HCP 022) for the first time. There is always that initial awkwardness to start with and that was very much on my mind. I was thinking I wonder what she thinks of me? Will she answer my questions without becoming defensive? Will she feel threatened? I must be careful how I approach her and how I speak! First impressions are so important! I must be myself but make an impression! Will she see that I am nervous about meeting her? Will we have time to establish some form of rapport? Returning to Dave, I just thought, great it's Dave and I know what he is like and he knows what I am like. However, there have been occasions when patients who do know me have given identical answers to certain questions in relation to the experience of treatment or issues associated with healthcare. They have adopted a defensive mode of "Oh I have no criticism – the treatment has been excellent – the consultants, the nurses are wonderful" and so on. Does the way in which I ask the question imply that there might be something to criticise or complain about? Is this because they see me as 'part and parcel' of the hospital team and know me as a nurse and not as a researcher? It might be that they feel that I am part of the establishment and that I might get offended if there is any criticism of care.

Knowing participants on a more personal level in relation to boundaries, and my role as researcher created some unanticipated issues. For example I was sometimes met at the railway station when interviewing participants in their homes. On one occasion the participant talked continuously while driving the car and may have been reluctant to repeat the whole conversation that had taken place prior to the actual interview. There was also the issue of the interview becoming more of a sociable event and transforming into a tea party when a couple seemed more concerned about their hospitality and making me feel welcome in their home. Was it essential that I made a distinction between an interview and the social nature of the event? Did this really matter as long as I got the desired data? Finding the right balance was something that I tried to achieve. Having said that, each interview was also different. Each person interviewed reacted in a unique way and it was assumed they expected me to be the same person that they knew (Simmons 2007). I was aware that acting differently for the sake of the 'researcher role' when there was an established and trustworthy professional nurse-patient relationship could have been insensitive to the interviewee, and potentially detrimental to the project.

3.9.3 Specific issues

A specific issue relating to time or the timing of recruitment created concern and was something that I was particularly aware of. People living with multiple myeloma may suddenly start to deteriorate so there was an urgency to interview

participants while they were well enough. Some may have died in the meantime. There was also the returning of transcripts for clarification which was not always appropriate or possible depending on the circumstances. In one case, for example, a young female patient died and I did not feel that I could return the transcripts to her husband and mother who had also participated in the research at a time of loss and bereavement. Even at a later date this may have proved to be painful and inappropriate. I felt reluctant to do this at any stage and risk causing undue distress.

The difficulties of being a novice interviewer were gradually overcome. Some of the interviews were particularly difficult for various reasons. Interviewing couples or a family group together was more complex. Difficulties arose when one family member's dominance took over the interview and the 'patient' allowed this individual to dominate. For example, I suggest that listening to two people speaking almost at the same time, observing body language and trying to pick up on important points but allowing them to continue without interruption required special interviewing techniques that are only acquired through experience. Novice researchers must learn to pick up on issues and allow the participant to talk more on a particular topic despite the fact that it may have been painful or critical. It seemed crucial to say something encouraging when necessary and not change the course or direction of the conversation because it was distressing. Any attempt to 'lighten' the conversation for instance and talk about something that was not so painful might have constrained the emerging theory.

The emotional impact on the person doing the transcribing was brought to my attention during the numerous conversations throughout the course of the study. This was a significant concern and one which required monitoring. The transcriber agreed to document the effect that the process was having during the transcribing of two particularly emotional interviews. A few lines of the transcriber's notes are presented below from one of the interviews:

"What a very sad life experience to narrate. How do people cope, you marvel at a human's resilience in the face of adversity, this young woman has certainly had to go through all sorts of traumas, emotionally and physically and she is so

young, it made me feel so very, very sad for them both. Your heart just wants to go out to them both. I felt quite tearful when transcribing this interview".

3.10 Managing the project

Organisation and administration were two important practical considerations for managing the project. The project administration file used on the computer is shown in a diagrammatic form in Appendix 16. This reflected the amount of paper work involved albeit on a much larger scale in reality. Examples of other files included:

- Field notes
- Transcripts
- Open codes and categories
- Research and Development Finance (record of invoices)
- Project work
- University docs (documents)

It was particularly important to keep records of the process and to document everything that occurred. This not only provided an audit trail but was a necessary organizational tool and useful for reminders and guidance. This prevented a lot of confusion especially half way through the project when, at times I needed to 'take stock' and ask questions such as:

- How many interviews had been done
- Who the participants were
- How many interviews had been transcribed
- How many transcripts had been coded
- Which transcripts had been sent away for data checking
- Which topics were emerging repeatedly?

These questions could be answered in an instant by looking at the updated interview record kept in the project administration file. The implementation of collecting, transcribing, and analysing data before the next interview was not always practical because the person transcribing lived 30 miles away and transcribed 3 or 4 interviews at a time. The mini discs from the recorder were posted by recorded delivery following the interview or delivered by hand to the transcriber. The recordings were listened to before and following the return of the transcripts. This was to (a) establish what the main issues were when another interview was pending and (b) to check the accuracy of the transcript. Each mini disc was labelled for identification with a number and the participant's

initials for example 099 PJS. The transcripts were e-mailed and the mini discs collected or returned by post.

Preparation for the interview was undertaken by using a checklist of items to pack in a bag and by routine checking of equipment. Before each interview the recorder was tested and the battery was checked. The checklist is shown below:

- Contact details of participant
- Mobile phone
- Pen
- Note pad for field notes
- Consent form
- Extra information sheet
- Demographic form
- Interview guide
- Diary
- Recorder
- Extra mini disc
- Extra battery
- Plug.

3.11 Managing the data

Another important practical consideration was managing the data obtained. The decision to use Nvivo qualitative software in this research project was based on the recommendation from members of the fellowship scheme funding committee. Nvivo was being used in the university prior to commencing the study and I welcomed the notion of learning a new skill and having the opportunity of using computerized assisted analysis to manage the data. The main advantages of the system were organization of data, storage of data, and retrieval of data. The following process memos reflected some of the difficulties encountered along the way:

Process memo
Nvivo software
Date: 25 May 2006

I am at the stage of open coding and organising the codes into category groups. In Nvivo the codes are nodes and the category groups are trees. The terminology therefore is simple. I attended an all day introductory workshop which was sufficient to start me off but not really adequate for my needs. I would have preferred a one to one tutorial and plan to go for a follow up

session, which they run at the University of Surrey. The whole day was whizzed through far too quickly for me to catch up with all the various functions. Not only are there various functions, there is more than one way of doing them which is confusing when learning something new. On the other hand, having more than one way of doing something can be advantageous and often when experimenting another way presents itself almost by accident.

Some of the difficulties I have encountered are worth documenting. I am disappointed that when placing the nodes into trees, this takes up so much time and appears to be a long-winded process. This is because the node browser immediately tells you which section or paragraph to go to but is not capable of going straight to that section of the data. On average each interview consists of 300-600 codes and it is necessary to return to the data checking for meaning and context while deciding which category or tree to place the code or node in. The system places the free nodes in alphabetical order. The whole process involves constantly scrolling the page up and down from say paragraph 4 to paragraph 1060 and visa versa.

A further difficulty I encountered this morning (hence I interrupted the analysis to write this memo) is that I have noticed on more than one occasion that sometimes there are 'double-ups' of sentences. I decided to delete a repeated sentence and lost both. Here the situation is that if you come out of the programme and do not save the changes then you risk losing the work that you have been doing. The obvious solution is to retype the sentence from the original transcript, however, the node browser has then become de-activated so it is necessary to make a note of exactly where in the text the node or code is situated, or spend time sifting through each paragraph until you find it.

Process memo
Nvivo software
Date: 06 September 2006

Having completed 014 yesterday morning I became frustrated with the vast accumulation of nodes from all transcripts. The system allows you to print out an up to date node list with or without full description. I like to be able to see an individual transcript's codes so I can return to them and the transcript at any given time. This is important and is the only way of returning to the data over and over again in order to understand the meaning and know what it is that the data are telling me. Once the nodes are placed into the trees (category groups) the only way to separate an individual transcript's coding is to firstly create a node list report, and then delete all except the one that you require. I have also been doing this as a backup by the re-entry of codes into another electronic system - a spreadsheet in Excel. Although this is time consuming, I think it is wise to have a backup on a different electronic system. It also serves to help with familiarization and meaning of data because everything is entered twice. The more interviews *that are done, the more data I am handling and this becomes a real chore when attempting to print out selected or an individual's node list. This is because of the sheer volume and the desire of not wishing to waste excessive amounts of paper. This means that out of 2457 nodes or codes I wanted to look at 241. The only way to do this apparently is to painstakingly and carefully pick out and delete all except for the 241 codes I wanted to view.*

This takes up considerable amounts of time and effort not to mention the fact that thousands of nodes equal hundreds of sheets of paper when printing.

3.12 Managing the time

The time scale and work plan (Appendix 17) indicated that by October 2007 I would be writing the first drafts of this thesis. The reality was that I had not had the last remaining five transcripts returned by then. Data collection was not completed until November 2007 and although I had not intended to do any more interviews at this time, a male Afro-Caribbean participant who had not been well enough to be interviewed previously contacted me stating he would like to participate.

3.13 Completed data collection

Data collection involved the undertaking of 46 recorded interviews as shown in Figure 3 comprising of 20 patient, 14 family member, and 12 healthcare professional interviews. In addition there were numerous e-mail communications, letters and field notes. All types of data can be used in the process of grounded theory (Glaser 1998). An interview record is shown in Appendix 18 illustrating that all interviews undertaken were transcribed and coded.

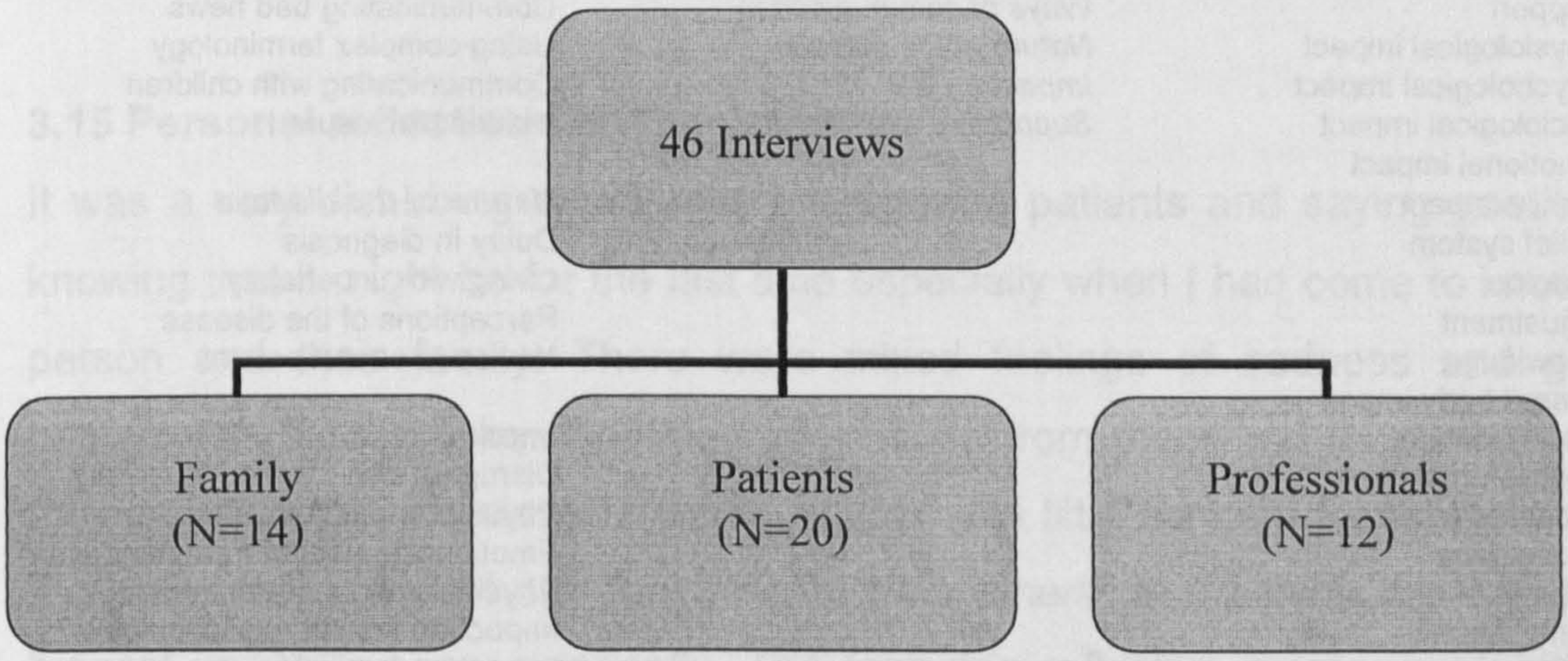


Figure 3 Completed data collection

3.14 Categories emerged from the data

A total of 25 category groups emerged from the data. Following the identification of the core category of *Contention*, it was then possible to be selective and identify which category groups related to the core category. Thus there is the process of integration of relevance and fit involving a process of delimitation. This is a momentous phase in the process of grounded theory research because suddenly there is direction and focus on development and consolidation of the main category groups identified. I found diagrams particularly useful to illustrate relationships between the core category and other category groups. One example of an evolving explanatory diagrammatic model is a thematic skeletal ribcage as the central bone (sternum) holds all the other bones (ribs) in place; that is they are all closely connected or linked together in the same way as the central or core category and associated categories or key issues as illustrated in Figure 4. Following the delimiting stage of the analysis, the four main category groups identified were: '*Ways of communication*', '*Nature of the disease*', '*Impact on life*', and '*Supportive care needs*'. These four main categories and their subcategories are introduced in more detail in chapter 4.

The 25 category groups, main categories and subcategories are listed below:

Category groups	Core and main categories	Subcategory groups
Communication	***CONTENTION***	***Ways of communication***
MM The disease		Communicating with the doctor
Support	*Ways of communication*	Communicating bad news
Physiological impact	*Nature of the disease*	Using complex terminology
Psychological impact	*Impact on life*	Communicating with children
Sociological impact	*Supportive care needs*	Hidden disclosure
Emotional impact		
Family impact		***Nature of the disease***
Belief system		Delay in diagnosis
Religion		Living with uncertainty
Adjustment		Perceptions of the disease
Knowledge		Novice to expert patient
Altered body image		
Understanding		***Impact on life***
Decision making		Disrupted life
Impact of others		Physical impact of disease
Acceptance		Emotional impact of treatment
Coping		Physical impact of treatment
Compliance		Impact on sexual relationships
Diagnosis		Impact on family life
Life		
Other diseases		***Supportive care needs***
Healthcare		Invisible struggle
Memory		Impact of policy
Perceptions		Decision-making

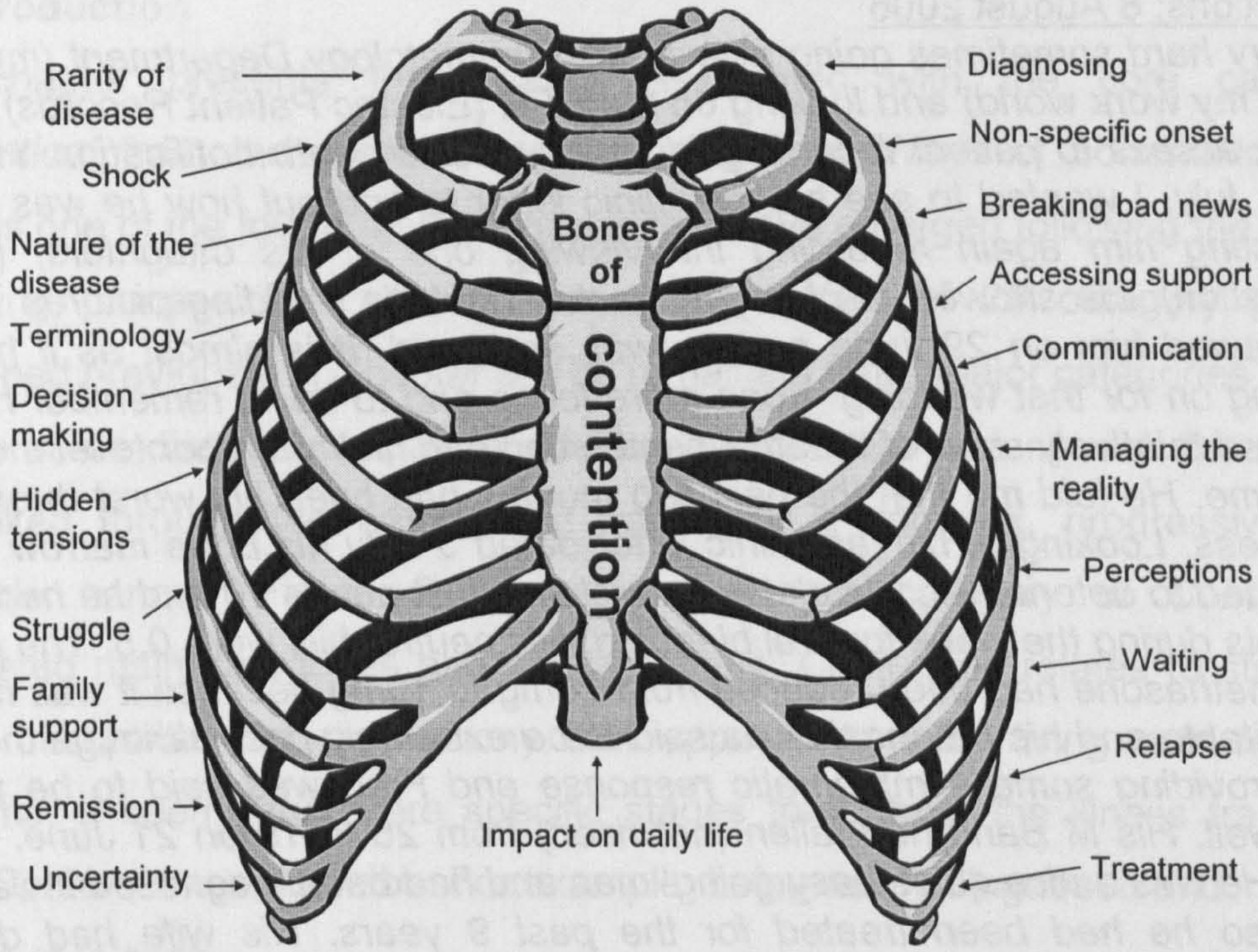


Figure 4 Evolving category group model

3.15 Personal reflections on the process

It was a very disturbing experience interviewing patients and saying goodbye knowing that it might be for the last time especially when I had come to know a person and their family. There were mixed feelings of sadness and guilt because as a researcher I needed information from them and as participants they gave up their precious time and energy with little concern for themselves. Typically people would say "anything to help others" and I think this had the biggest impact on me personally. The following reflective memo was written following awareness of Fred's (P 017) death.

Reflective memo
Reflections: 8 August 2006
It's very hard sometimes going over to the Haematology Department (my other world, my work world) and looking on the EPR (Electric Patient Records) where I have access to patient records and finding Fred's death notification. He died on 24 July. I wanted to see his last clinic letter to find out how he was before contacting him again regarding interviewing one of his daughters, (Fred's suggestion). He showed me his youngest daughter's wedding pictures when I interviewed him on 29 June and he was so proud. It is almost as if he was hanging on for that wedding – one more loose end to tie. I remember he was pale and relatively short of breath when he came to his front door to let me into his home. He told me that the past two months had been his worst throughout his illness. Looking at his last clinic letter dated 3 July his bone marrow failure continued to deteriorate. His platelet count was just above 10 and he had some platelets during the week for oral bleeding. His neutrophils were 0.5. The pulsed Dexamethasone had been reduced from 20mg to 10mg because it was making him irritable and his prognosis was said to be extremely poor although the Dex' was providing some symptomatic response and Fred was said to be feeling fairly well. His M Band had fallen (not risen) from 26 to 19 on 21 June. I liked Fred. He was a nice quiet 'easy going' man and had been diagnosed in January 1997 so he had been treated for the past 9 years. His wife had died of leukaemia at (named hospital) in 1989. Fred had two married daughters and a grandson. I am sure he will be greatly missed.

3.16 Summary

This chapter has delineated an overview of the research process. There has been an account of the planned investigation and how this was managed in reality discussing some of the difficulties along the way. General methodological issues were discussed in relation to the conflict in the literature between Glaser and Strauss because of the remodelling of grounded theory resulting in different approaches. Specific methodological issues relating to the undertaking of the project were also highlighted. Managing the project took into account practical issues such as preparation of interviews, organisation of administration, the importance of keeping records and providing an audit trail. The initial 25 category groups and the consolidated main categories and their subcategories are introduced. The next chapter introduces the participants, presents findings and the generation of theoretical interpretations from each participant group.

Chapter 4. Findings

4.1 Introduction

This chapter presents the findings associated with the core category '*Contention'* from the research commencing with 'Ways of communication', which is one of the four major categories that have emerged following the delimiting process and consolidation from a total of 25 category groups mentioned previously in Chapter 3. The remaining three major categories are: 'Nature of the disease', 'Impact on life' and 'Supportive care needs'. Categories are linked through the nature and impact of a complex, progressive and incurable cancer. Figure 5 illustrates the core category of *Contention,* associated main categories and subcategories. *Contention* relates to struggle, battle, disruption and disharmony that appears to exist living with multiple myeloma. It seems there are specific stages throughout the illness trajectory when *Contention* crescendos. For example, being newly diagnosed and periods of relapse.

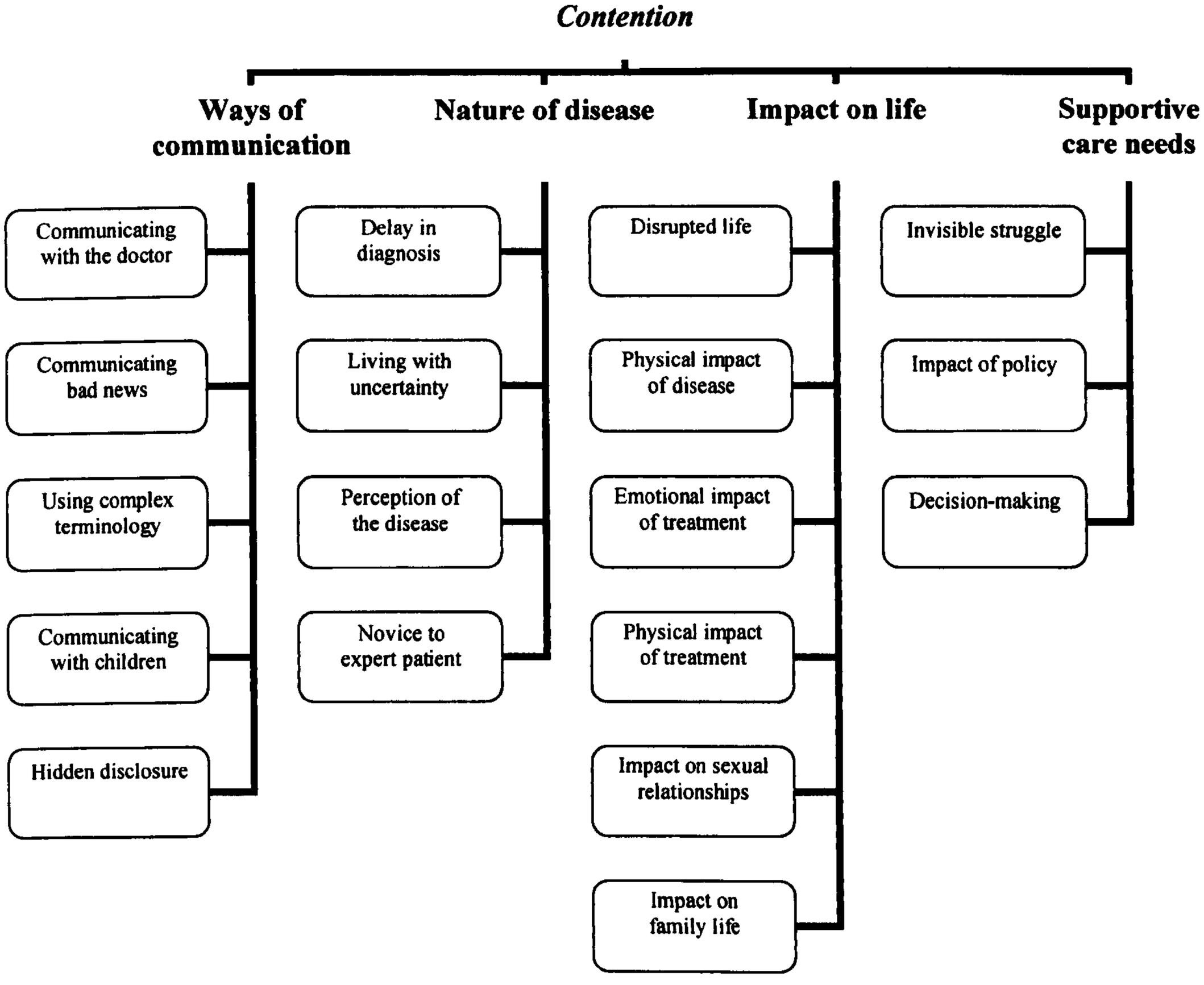


Figure 5 Core category Contention, main categories and subcategories

This section of the thesis begins with introducing the participant groups. Memos consisting of patient and family profiles introduce the participants' background stories which follow prior to the presentation of findings. Beneath the headings of each main category follow the named subcategories associated with them. Contextual and analytical story lines provide theoretical explanation, and conclude each of the subcategory group sections. A summary concludes each of the main categories and their subcategories. Lastly, in order to illustrate a diagrammatic representation of the core category '*Contention*', major category groups and subcategories within the context of an incurable and progressive haematological malignancy, is presented in Figure 6. The chapter ends with a final position statement creating an opening for the next (discussion) chapter.

Selected extracts from interview transcripts are used to illustrate points within the text. Vignettes from chosen transcripts are also displayed in trilogies with the aim of presenting exemplars from each group of participants (Tables 3-21). This provides a way of presenting the participant groups collectively in order to substantiate the findings. This approach was inspired by accessing a grounded theory thesis about decision making for ill children (Baxter 2004).The interviewees are identified by the letter P for patient, F for family member and HCP for healthcare professional. Each participant has a study number, for example P 001 is a patient allocated with number one, F 002 is a family member and participant number two and HCP 005 is a healthcare professional and participant number five. Participants in this study attended various hospitals and the names of these are omitted and replaced with (named hospital). Pseudonyms are used for patients, family members and healthcare professionals throughout in order to maintain confidentiality.

4.2 The participants

Patients and family members are introduced first. These are introduced as: couples, small family units and individuals; using pseudonyms, age range, occupation, date of diagnosis and in some cases, a second date indicates date of death (Table 1). Healthcare professionals are presented in Table 2. Descriptive patient and family profile memos are then displayed introducing the patients' and families' background stories.

Patient and family pseudonyms. Age range, occupation and significant dates

Bert and Shirley	61-70	Retired engineer, diagnosed 2003-2006
Bill and Sylvia	41-50	Electrician, diagnosed 1997
Pam and Alf	61-70	Retired printing, diagnosed 1987-2007
Frank and Maggie	61-70	Retired policeman, diagnosed 2002-2008
Debs, Mat and Stella	30-41	Architect, diagnosed 2004-2006
Geoff and Carol	51-60	Administrator, diagnosed 2001
Jack and Penny	41-50	Research market, diagnosed 2002
Marian	61-70	Retired Home Help 2000-2001
Fred	61-70	Retired BT engineer, diagnosed 1997-2007
Sally	61-70	Retired lecturer, diagnosed 2004
Phil	61-70	Retired IT Bank, diagnosed 2002-2007
Dave	41-50	IT Architect Bank, diagnosed 2003
Gloria	51-60	Retired domestic supervisor, diagnosed 2006
Maurice	61-70	Retired mechanic, diagnosed 1993
Charlie	41-50	Ambulance driver, diagnosed 2006
Victor	51-60	Teacher, diagnosed 2007
Alice, Val, Rosemary	71-80	Retired secretary, diagnosed 2001
Mike	51-60	Retired plasterer, diagnosed 1993

Table 1 Patients and family members

Healthcare professionals (with pseudonyms)

Lin, Myeloma Clinical Trials Nurse
Ruth, Bone Marrow Transplantation Coordinator
Sam, GP
John, GP
Karen, Myeloma Nurse (Clinical Nurse Specialist)
Ian, GP
Pauline, Macmillan Palliative Care Nurse
Ellen, Macmillan Palliative Care Nurse
Jill, Haematological Oncological Nurse (CNS)
Maura, Myeloma Nurse (CNS)
Claire, Myeloma Nurse (CNS)
Fiona, Myeloma Nurse (CNS)

Table 2 Healthcare professionals

4.2.1 Patient and family profile memos

Bert's story:

Bert (P 001) and Shirley (F 002) were married with two adult children. Bert was a retired engineer and Shirley a retired occupational health nurse; both in their late sixties, articulate and friendly Caucasians living in Essex. I had met this couple while working as a clinical trials nurse prior to the commencement of the research. They were staying in a flat in London isolating themselves away from their family and friends while Bert was undertaking his first chemotherapy. This decision was based on the assumption that the isolation would reduce the risk of infection, as Bert was prone to chest infections. Bert was feeling particularly vulnerable due to a number of infections resulting in treatment delays. This couple were interviewed in 2004 (Bert had been diagnosed for approximately 4 months) and again in February 2006. They were interviewed separately on the first occasion and together for the second. It was during the first interview that I saw an emotional side of Shirley I had not seen before. The difference between 2004 and 2006 was plainly evident in the way they both reacted during the interviews. This couple were initially in a vulnerable and uncertain frame of mind. I hadn't anticipated the emotional impact on Shirley and her need to talk to someone which was not only extremely fundamental but provided an insight into each of their perceptions of the illness and the impact this had on their lives and that of their family and friends. I had seen a caring and supportive wife accompanying her husband when he attended the chemotherapy day care unit. I knew Shirley had been a nurse and appreciated that she was not familiar with the world of haematological oncology but she was learning at a rapid pace. Shirley seemed in control, always smiling and very attentive. During the second interview I could see this massive difference. The disease and the implications of the myeloma were no longer a new concept as when Bert was newly diagnosed and starting his first chemotherapy. Shirley and Bert had now been through periods of 'ups and downs'. They appeared knowledgeable, relaxed, confident and in control of their lives.

Pam's story

Pam (P 003) and Alf (F 004) two bubbly personalities residing in Essex, were married with 2 adult children and 3 grandchildren. Pam was diagnosed in 1987

with multiple myeloma when she was 47 and employed full time. Pam attended an osteopath for back pain on three or four occasions before deciding to go and see her GP. Her back pain became so severe that she was unable to climb up the stairs to go to bed. Over a period of a few days her condition deteriorated and she was admitted to hospital by ambulance in a semi-comatosed state having vomited several times. Pam's blood was described as being 'like syrup' and she was immediately dialysed (urgent plasma exchange). Blood tests and bone marrow biopsy confirmed the diagnosis. Pam's first remission lasted for 12 years, which is unusually long. During the time following Pam's first treatment regime Alf and the children had discussions about the potential life expectancy, which they understood was approximately five years. They avoided telling Pam about the five-year life expectancy and made sure that she did not have access to medical texts. Alf made a number of decisions concerning the kind of information to which his wife should or should not have access. He did not want to talk to her about anything that was in his view 'negative' and it was of paramount importance to him, that she remained in a positive frame of mind and not take 'hope' away.

Frank's story

Frank (P 007) was in his late 60s, originally from Scotland and married to Maggie (F 008) who was Irish. I met this couple in 2002 when Frank was newly diagnosed. They had three adult children and lived in Essex. He had retired from the police force and was working part time in an office prior to the onset of illness. The day of the interview was freezing cold (March 2006) and Frank and Maggie had been to Mass, which finished at 09.30. I was expected at around 10.00. Frank was a tall man, good head of hair, wore spectacles, had a large body frame and was very friendly. Frank had a strong Glaswegian accent and he walked slowly but unaided as if he were treading on sacred ground. His walk was impeded by the neuropathy (numbness in his feet) causing discomfort. He was cheerful and welcoming and not for the first time I felt humble in his presence. My impression of Frank was that he was a strong character and very set in his ways. Frank epitomized the uncertainty and disharmony associated with living with multiple myeloma by using the analogy "*It's like living with the sword of Damocles over you all the time*". This couple were also interviewed

twice but the second time was a validation of research findings visit. Frank was very interested in medical topics and was knowledgeable about his disease, medication, treatment options, specialised surgical procedures and investigations.

Deb's story

Debs (P 009) was a young mother married to Mat (F 010) and the daughter of Stella (F 013). Debs had contacted me by e-mail suggesting an interview date and informed me that her 'mum' was interested in participating in the study also. Debs had broken both her hips and was waiting to have surgical hip replacements. I met her and Mat at their home for the interview. Debs and Mat were in their mid thirties, both had degrees in architecture and met at work in 1998. They started dating in 1999 and had a toddler aged 3 (Ben). They lived in East London in a terraced house, in a narrow and congested street so parking was a real problem, as they did not have a garage. Debs was managing to manoeuvre fairly well with crutches. On the day of the interview she was dressed in a black Tee shirt, black trousers and comfortable looking beige laced trainers. Her body took on the shape of the letter Z. Her back appeared bent forwards and her hips seemed to protrude outwards from behind which were more obvious from the side view. Sitting down she looked normal with a small body frame and a young pretty face. However, Debs she had lost significant body weight although she had started to regain a little. Her hair was very short having just grown back following recent high dose chemotherapy. This family were having a difficult time and the interview was emotional particularly because Debs was pregnant at the time of diagnosis. The pregnancy was terminated and chemotherapy was commenced immediately following this extremely distressing event. Debs described the turmoil to her life as being ongoing with one thing after another. She was distraught and frustrated because of the problems with her hips, not being able to walk, return to her job or take care of her little boy.

Geoff's story

Geoff (P 011) who broke his arm while swinging his golf club was married to Carol (F 012). Geoff and Carol were in their early 50s and lived in Essex. On

the day of the interview, Geoff was having his monthly pamidronate infusion (to treat bone disease) on the Day Care Unit and his wife who worked part time in a GP's surgery usually had the day off on Mondays so she joined him. Geoff was a tall quiet man with black hair; he was dressed in slacks, blue open necked shirt and navy anorak. He told me he had the day off work and appeared relaxed. Normally he would be 'booted and suited' like Dave (P 023) and on his way to work. Carol was dressed smartly in a matching dress and jacket. They were a good-looking couple and both appeared healthy. They had three adult children (a son and two daughters) who had now left home with the exception of their son who was away at university. I first met this couple in 2002 and looked after Geoff when he participated in clinical trials during two periods of relapse. Geoff had been relatively fit and healthy before he was diagnosed with the exception of pain in his right arm which only caused discomfort at particular times for instance when turning the steering wheel in his car. Geoff rarely showed any emotion and often appeared expressionless. Getting him to talk was a challenge as he was a shy, private person. It took time to get to know him.

Jack's story

Jack (P 014) and his wife Penny were in their mid forties and lived in East London. They met as teenagers and Jack was diagnosed with multiple myeloma in 2002 four months after the birth of their son Nathan. Jack and Penny were very articulate, friendly and easy to talk with. Jack began having problems with his back after they had moved to a new home before Nathan was born. Jack was attempting to construct a massive pre/flat packed wardrobe. This was a lengthy and difficult job as the wardrobes' parts were extremely heavy. Jack thought he had slipped a disc and injured his back during this time. The back pain got steadily worse while building the wardrobe and he went to see the GP for some pain relief. The analgesics were ineffective and he started to feel sick. The GP assumed that the medication was causing the sickness and so the analgesics were changed for a new prescription. During the months prior to the diagnosis Jack visited his Father (a doctor) in Canada who advised him to request an MRI scan, as the pain was persistent and debilitating. Jack requested to see a 'bone specialist' privately and was finally diagnosed. At the

time of the interview Jack and Penny were planning on (moving home) returning to Canada. Jack's condition had deteriorated and he had been unwell for a long period of time. He had relapsed and things looked bleak, as he was no longer responding to treatment. Penny continued to work as a newspaper journalist in the evenings and the couple struggled to find help to take care of Nathan who was 4 years old. They had no family living in the UK. Jack's story encompasses many issues impacting on family life including his frustration due to loss of control as a 'Dad' such as not being able to lift his son up or assist in looking after him.

Marian's story

Marian (F 016) a bereaved daughter, worked as a specialist renal nurse employed at one of the large NHS teaching hospitals in London. Marian was also a fellow PhD student. We were introduced to one another during the time we were going through the application process of securing university placements. Marian's mother died in February 2001 having been diagnosed in July 2000 leaving her family completely devastated. Her parents had been married for 40 years and they had four daughters, one of whom was fostered, and a son. The interview took place in a quiet room at the university. Marian stated she would probably get upset and she did start to cry at one point. It must have been very difficult for Marian speaking about her mother's illness and then bereavement especially when it all happened so quickly in a space of a few months. Marian, however, viewed the interview as a cathartic experience. Marian's mother was diagnosed quickly as she had been monitored for approximately two years. She had originally seen her GP with a history of bad headaches and following a number of visits a blood test showed some "*abnormality*" necessitating referral to haematology and a period of monitoring. The onslaught of the disease was indeed an aggressive one. Marian describes the illness as "*hell on earth and no quality of life in between*" and portrayed a vivid picture of her mother's deteriorating condition (Smith and Cox 2007) and the emotional strain on the family. Marian was able to see the physical changes that other family members could not and privately regarded her mother as a *'dying cancer patient'*. Despite her private feelings and observations Marian was

able to convince family members that her mother's condition was improving to maintain some semblance of hope.

Fred's story

Fred (P 017) was a widower in his mid 60s who lived in Essex. He retired early at the age of 50 to spend more time with his two adolescent daughters having lost their mother who died of leukaemia. Fred was a pleasant, quiet, and smartly dressed man who I had treated on the chemotherapy day care unit and seen during his hospitalisations over the past five years. He was diagnosed in 1997 which he said *"was fairly devastating"* as he felt he was *"immune"* particularly having seen his wife die in 1989 of myeloid leukaemia. The interview took place in June 2006. Fred, a deceptively healthy, normal looking man was wearing a short-sleeved shirt and shorts. I noticed he looked pale and was a little short of breath. Fred showed me photographs of his youngest daughter's recent wedding. He had two married daughters and a grandson. I got the impression he was comfortable living on his own. Fred had a lot of good friends, some of which he has grown up with and kept in touch all through the years. It was several years and numerous visits to the surgery before Fred's GP finally investigated the cause of his pain. Fred had been diagnosed for nine years and he stated that the last two months had been particularly difficult because he now felt that he was running out of options and his body could not take much more. Fred thought 'the tablets' were causing too many problems and wondered if it is was worth taking all the medication. Fred answered his own question by stating that on the other hand he would not have survived as long as he had without the medication. Fred's quality of life had been relatively good up until this point in time.

Sally's story

Sally (P 018) was a 61-year-old spinster and retired college lecturer. She had lived in a small first floor self-owned flat in Essex for 28 years. Sally was another patient I met when she was first diagnosed. Her hair had grown back (post chemotherapy) and she seemed different. Sally was in control of her life again. She was well, confident and appeared normal. Since her stem cell transplant Sally had been well for a year. Initially Sally had palpitations and had

gone to see her GP who arranged for her to have numerous blood tests. She was informed by her GP that there was the possibility of a "suspected" myeloma. Sally felt *"shattered"* despite the fact that she did not know what myeloma was at that time. During her first line of chemotherapy Sally spoke of not understanding about what the medication was doing to her body and mind. She talked about the steroids and said "*I didn't understand what was happening to my body because of the drugs and the most wonderful thing was being in control. Do you remember when I refused the medication? I wanted to tell you to get stuffed and I did*! *It felt so good so I missed that last dose of chemo. This was the thing, you were totally in the hands of the clinician and I can remember saying to Tom* (registrar) *please tell me that what you are doing is going to work*". Sally needed constant reassurance. She spoke about being positive and how important that was. Sally portrayed the aftermath of high dose chemotherapy (stem cell transplant) when she lost all levels of concentration and thought she was losing her mind during the time she was in the hospital room recovering.

Phil's story

Phil (P 019) was a tall man with a thick head of white hair and a pleasant face. He was originally from the USA and had been divorced four times. Phil's accent sounded almost Cornish with a slight American twang. He had lived alone for the past eight years and had three adult children – one son and two daughters. He saw at least one of his children every weekend. Sean, his 18 year old son accompanied him on the day of the interview which followed a routine clinic appointment. Phil walked towards me waving and smiling wearing dark blue jeans and a dark terracotta long sleeved shirt. He had put on some weight probably due to the steroids. Phil looked pale and tired, but apart from that he appeared well. Phil appeared confident and relaxed. He was intelligent and knowledgeable about the disease and viewed almost everything as an *"adventure"*. Phil's Father died of myeloma (unusual and unproven hereditary link) and he felt that his mother was probably more shocked about his own diagnosis than he was. He left home when he was 19 and wasn't around when his Father was ill so had little knowledge of the impact on his mother or sister. Phil was well into the 'internet world', which was natural for him as he was from

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Phil's story

Phil (P 019) was a tall man with a thick head of white hair and a pleasant face. He was originally from the USA and had been divorced four times. Phil's accent sounded almost Cornish with a slight American twang. He had lived alone for the past eight years and had three adult children – one son and two daughters. He saw at least one of his children every weekend. Sean, his 18 year old son accompanied him on the day of the interview which followed a routine clinic appointment. Phil walked towards me waving and smiling wearing dark blue jeans and a dark terracotta long sleeved shirt. He had put on some weight probably due to the steroids. Phil looked pale and tired, but apart from that he appeared well. Phil appeared confident and relaxed. He was intelligent and knowledgeable about the disease and viewed almost everything as an *"adventure"*. Phil's Father died of myeloma (unusual and unproven hereditary link) and he felt that his mother was probably more shocked about his own diagnosis than he was. He left home when he was 19 and wasn't around when his Father was ill so had little knowledge of the impact on his mother or sister. Phil was well into the 'internet world', which was natural for him as he was from

an IT career background. Phil was a resourceful character and very proactive at accessing support and finding ways of helping himself. Phil exercised his fingers and stated that his own *"physiotherapy"* had been very effective. Phil believed that typing on his computer was good exercise as he was moving all his fingers and thought this helped significantly with his neuropathy.

Dave's story

I met Dave (P 023) for the first time when he was newly diagnosed and have looked after him when he attended the chemotherapy day care unit on numerous occasions. Dave met his wife when he was 19 years old and they started dating having known one another for 7 years. They married in 1993 had a daughter aged 7 years and a son aged 5 years. Dave was in his early forties, tall, fairly slim, had dark hair, wore spectacles, and was smartly dressed in a suit when he attended clinic as he was usually on his way to work or a meeting. He worked in London and had a passion for politics. He appeared confident and well educated with a clear and fairly distinct loud voice. The day of the interview he seemed to be his usual cheerful and optimistic self but remained pale and slightly bloated in appearance due to steroids. Dave was a local counsellor within the community where he lived in Essex and had an interest in Martial Arts, which he gave up when diagnosed. Prior to the interview Dave told me that his Father had died from lung cancer recently at Christmas time. His Father often accompanied him to the hospital and appeared well. Dave's Mother had died 5 years previously from breast cancer. I had never met Dave's wife or his family except for his Father. Dave attended the chemotherapy day care unit regularly because his paraprotein levels had been "*up and down like a Yo-Yo throughout*". According to Dave he had not experienced long periods of time when the MBands or paraprotein levels were low. Despite this Dave appeared to be very optimistic and full of enthusiasm. He seemed to 'bury his head in the sand' although he was knowledgeable about the illness and its outcome. Dave appeared to keep his working life, his family life and his hospital life as separate entities. The physical impact of the disease was explained in terms of "*catastrophic lack of fitness*" and the pain in his hips was described as "*like someone had applied sandpaper to the joint*".

Gloria's story

Gloria (P 024), was the first patient I interviewed who was not known to me previously. We had spoken on the telephone on several occasions prior to the interview which took place in her home. She was introduced via one of the registrars from the clinic and I was told I could call her directly. Gloria was a 67 year old widow originally from Barbados. She had three adult sons one of whom still lived at home and had five grandchildren. Gloria had lived in her maisonette in East London for 27 years. She had a kitchen downstairs but needed to walk upstairs to the lounge and bedrooms. Gloria described how ill she had been and how wonderful she thought the doctors and nurses were at the hospital. She talked about her chemotherapy and stem cell transplant. Gloria appeared well and was in remission (stable disease). Gloria described her treatment as "*plain sailing*" and seemed aware of other myeloma patients who have had a number of set backs and treatment delays. Gloria was also aware of patients not responding to treatment and felt thankful that she was "*fine with it all*". Gloria had been diagnosed the previous year and had one line of therapy which included high dose melphalan and stem cell transplant. Gloria had not yet endured the numerous relapses and treatments that other participants in this research had. It seemed she had a lot of energy and drive. Gloria maintained that she viewed things differently because of the illness. She was no longer interested in the material things in life but in the environment of her home and family. Her religion and faith in God was very much part of her life and significant. Gloria felt grateful that she had "*been saved*" however she knew there was no cure and understood that the myeloma would return in due course.

Maurice's story

Maurice (P 025) who was originally from Sierra Leone in his mid sixties, lived in the UK since 1960 and had two adult sons (ages 26, 31 years) living at home. Maurice was introduced to me by the consultant haematologist who had given him an information sheet and had explained about the research project. Maurice appeared reluctant for the interview to be held in his home and suggested that we met at the chemotherapy day care unit on his clinic day. He was accompanied by his sister who drove him to the hospital as his wife was at

work. Maurice's sister waited outside the room during the interview. Maurice was attached to his pamidronate infusion (to control bone disease) pump which constantly ticked like a clock. The room was small and the noise from the street outside was disturbing. The place was thriving and the interview was difficult because Maurice spoke very quietly, almost mumbled when speaking and had very little if any eye contact. Maurice was not very informative. His answers were short and he seemed unable to discuss things in any great depth. He appeared very lethargic and 'out of sink'. I do not think he was aware that he kept repeating the same things over and over again. Maurice was emotional throughout the interview. He has attended the day care unit for several years and was described by nursing colleagues as always 'cheerful and fine'. He seemed to have pent up emotions, spoke a lot about the pain he had suffered over the years and did not want to be a burden to anyone. He disclosed that he had a *"few tears lately"* and when his wife asked him what the problem was he was not able to talk because he felt as if he was going to be a nuisance to his family: "*when the bad days they come I just try, as best as possible to ... get over it ... and then ...but most of it is a nuisance to the family, you just, try to just take it*".. Maurice was diagnosed in 1993 and appeared to have limited knowledge of his illness. The main topic of conversation evolved around Maurice's progressive bone pain and his entire demeanour spoke volumes suggesting a man who found his situation intolerable.

Bill's story

Bill (P 027) was the first patient I met with multiple myeloma when I first started working at the hospital. Bill and his wife Sylvia met on a blind date and had been married for 21 years. They seemed devoted to one another. They did not have any children but had three small dogs. They both had elderly parents who were living fairly close by but independent. Bill's mother had blood cancer of the platelets (diagnosed after Bill). His father also had surgery for cancer of the colon. Bill was diagnosed in 1997 at the age of 42 and worked as an electrician having set up his own company. Bill had been suffering with 'back problems' for several years and was working seven days a week until he could no longer move. He had driven from Essex to London on his last day at work and was unable to get out of his car to do a job. Bill telephoned the people who were

expecting him while sitting in his van outside their home and informed them he was unwell and then managed to drive home. Sylvia had to lift him from the car and help him into the house where he laid on the floor with multiple vertebral fractures. Following the onset of the illness Sylvia spent several months worrying about their finances and had borrowed money from close relatives as Bill was no longer able to work. Sylvia visited her husband every day while he was in hospital and she would tell him that everything was fine. The reality was that they had very little money and she would not burden him with what she considered to be an additional worry or cause him further anxiety. Bill and Sylvia were interviewed a second time three years later in June 2007.

Charlie's story

Charlie (P 029) was an Afro-Caribbean born in 1965 and had a happy and sunny disposition. Charlie was diagnosed in 2006. He had a clear East London accent and seemed 'on the ball'. Charlie lived with his partner Christine who worked part time. She reduced her working hours when Charlie became ill. They had lived together for 16 years. Charlie had fathered four children, the youngest of whom was Christine's and Charlie's 10-year-old son Kevin who lived with them. Charlie spoke to his consultant haematologist about Kevin because he was worried about talking to him and explaining to him about the cancer. His son knew that his father was sick but did not know what was causing the illness. Charlie stated "*I didn't know, we didn't know how to tell him about it*". Charlie was introduced by a nursing colleague who had spoken to him about the study. I met him for the first time on the day of the interview. Charlie had stated that he preferred to come to the School of Nursing (university) for the interview and was glad to get out of the house and have something to do. He was wearing a white baseball cap, striped tee shirt and track-suit trousers. Charlie had travelled by bus, as he did not feel ready to drive again just yet. Charlie also thought that he needed more exercise. Charlie told me that he had three uncles (mother's brothers) who each died of cancer. Ironically Charlie worked as an ambulance driver picking people up from the chemotherapy day care unit (hospital transport). He had not been able to work since October 2005. He was diagnosed in February 2006. Charlie reiterated a typical presentation of an assumed slipped disc as the probable cause of his back pain which was

becoming unbearable over a period of time. Initially Charlie was unable to stand up and was crawling about on hands and knees, which is not an uncommon scenario.

Victor's story

Victor (P 030) was introduced by one of my nursing colleagues. Victor, a tall Afro-Caribbean age 52 years with greying hair and a small white beard was a quietly spoken and articulate gentleman. Victor was teaching adults literacy, numeracy, and computer skills. The interview took place at a flat in Homerton close to the railway station where Victor had been staying with his partner. Victor instructed me to meet him at the entrance of the block of flats and as we went up in the lift to the small flat he stated he was very tired which in his view was his major problem. He spoke quickly and almost in a whisper; I thought that the recording from this interview would not be audible due to Victor's quiet voice. Victor lived with his 21-year-old daughter who was currently away at university. Since his illness he had been staying with his partner and their son who is totally deaf aged 11 years old. Victor has fathered six children. His younger sister died of Lupus age 27 and both of his parents had also died. Victor was with his sister when she became ill and remained with her until her death. She had also been a teacher. They grew up together and spent time travelling together. When he lost his sister he said his mother lost the will to live. He was the last of 10 children who remained at home looking after his elderly parents. His brothers and sisters came to the UK in the 1960s while Victor arrived more recently in 2003. Victor's invisible struggle was not understanding the system and not knowing what benefits he may be entitled to although he was able to search on the internet for the information he required. Victor was also having problems with the company for which he worked. His manager appeared to be unsupportive, uninterested and unaware of the severity of the illness.

Alice's story

Alice (P 033) and her two daughters were introduced by the consultant haematologist while they were waiting to be seen for a routine check up in the outpatient department. Alice was a 'young at heart' elderly Afro-Caribbean lady

who appeared well but unable to walk very far. Her daughters (Val and Rosemary) pushed her in the wheel chair to the university room where the interview took place several weeks following the introduction. Val seemed very much in control and although the family came as a complete package I believe that the outcome of the interview would probably be very different if I had been able to see them individually. The family did not want me to visit them in their home and it was decided I could interview them as a group on a day when they came for a clinic appointment. When I asked Alice if she could talk about the illness and what was happening to her she replied that she "*can't understand what's wrong*" and that she had a pain in her back, which seemed to be improving. Alice made a reference to the alteration in her body image explaining that on standing she tends to lean forwards because of her back problems. Val (F 035), on the other hand, talked openly sitting close to her mother about her understanding stating that multiple myeloma was a type of blood cancer and spoke of the impact on bone. Val also used the word *"terminal"* and I watched Alice and her younger daughter to see their reactions. Rosemary seemed uncomfortable and her mother appeared to display no reaction giving nothing away. I understood Alice could hear well and although she might not be familiar with the word 'terminal', most people understand the word 'cancer' and it therefore suggested that she chose not to hear. I was disappointed with the interview as this family responded with very short answers or brief comments. They seemed reluctant to talk in any depth or detail. They did not appear to have very much to say and I got the impression their responses were staged. I asked Rosemary (F 034) if she worried about her mother relapsing and she changed the subject by saying *"everything will be alright"*. Was she protecting her mother from the knowledge that perhaps she was concerned? Was this her way of dealing with the situation? Rosemary did not say very much. She seemed 'closed' but 'zoomed in' on the positive aspects. She was keen to tell me about the sort of person her mother was, that she was always positive about things and would want to carry on the best she could. I wondered how the family were dealing with the reality of the situation emotionally and if they talked to one another about the cancer.

Mike's story

Mike was a 56-year-old Afro-Caribbean who was diagnosed with multiple myeloma in 1993. Like Gloria (P 024), he was of a sunny disposition and deeply religious. He had a laid back attitude. Mike walked slowly with a stick to aid him and appeared very tired. Mike was still able to drive and relatively independent. He had a supportive wife and caring adult children some of whom still lived at home. Mike's 19-year-old daughter had grown up throughout the illness trajectory. Once engaged in discussion with him his humour shone through. Mike was intelligent and articulate although he had not studied the disease to the extent that he could be categorised as an 'expert patient', but he was most definitely an experienced patient. The interview was held in a room at the university. Mike was dressed in a leisure shirt, dark navy jacket, track-suit bottoms, trainers and white baseball cap. His hand felt cold when I shook it. I asked him if he would like a hot drink and made him a cup of tea. I tried to select the most comfortable chair for him to sit on. We sat chatting for a while before the interview. He seemed very relaxed and happy to just sit and talk before and following the interview. When he was in his teens he was assaulted by a gang of youths and kicked in his left lower back repeatedly. It is in this same spot that the myeloma tumour emerged several years later. Mike worked as a Plasterer and we talked about the possibility of chemicals or toxins in industry and their potential association with the disease. Mike had metal plates and screws, which were supporting his collapsed vertebral bones. He thought the metal plates were creating pressure on the nerves and causing cramps in his legs and upper thighs. He had a lot of pain in his legs and ribcage and only got partial relief from the medication, which he tolerated. He was very grateful for all the help and support he received from the hospital staff and made a point of repeating this twice which made me feel that perhaps he felt I was expecting him to complain or criticise the care and treatment he had received. The main issue or worry that Mike spoke of openly and spontaneously was the swelling or tumour on his penis, which has had a monumental impact on his life and sexual relationship with his wife

4.3 Ways of Communication

"There are a lot of assumptions made by the medical profession, when they're talking to you, that you understand their 'jargonese' and this is one of the problems that I think needs to be addressed" Bert (P 001).

4.3.1 Introduction

This section of the findings chapter introduces '*ways of communication'* the first of four main categories, which form an integral part of the core category of *Contention*. The findings are presented addressing each main category and associated subcategory headings set out within the context and analytical story lines. Extracts from transcripts are used within the text and also displayed in trilogies (Tables 3-21) corresponding to the analytical story lines. The analytical story lines provide emerging theoretical explanation (Strauss and Corbin 1998).

'Ways of communication' relates to the ways in which individuals and their families interact and behave towards others (and how others behave towards them) during illness. *Contention* in communication may imply emotional conflict, disharmony, feeling ill at ease, confused and feeling overwhelmed. The above quote (Bert 001) is a reference to healthcare professionals using medical terminology when communicating which created difficulty particularly when newly diagnosed and unfamiliar with the language associated with multiple myeloma and its treatment. The findings suggest that some of the participants experienced feeling rushed during consultations and that they might not be prepared or able to take on board additional information concerning treatment when they are still coming to terms with the diagnosis:

Shirley (F 002)
"Things were all falling into place but it was the speed of it and it was Tom (consultant) *who said undoubtedly you've got multiple myeloma and I think we were both....well lets find out more about it....He did explain - he came over so fast and furious ....that we had to stop him half way through because he was going into the cycles, and it was just overload"....*

The subcategories of *'ways of communication'* include: '*communicating with the doctor*', '*communicating bad news*', '*Using complex terminology*', '*communicating with children'* and '*Hidden disclosure*'.

4.4 Communicating with the doctor

4.4.1 The context

The ways in which people communicate with their GPs during the pre-diagnosis stage vary considerably from seeking minimal information relating to symptoms, (which may be because the onset is often nondescript), to articulating the same problem repeatedly, (often bone pain). Some of the patients participating in this study had reached crisis points and were admitted to hospital by an ambulance requested by the GP during a home visit. A typical period of time between initial contact with the GP and confirmation of diagnosis ranges from months to years depending on the severity of symptoms. Fred (P 017), for example, frequented his GP's surgery with the same problem several times over a period of years. He was unable to say exactly how many years but presented with a pain in the side of his chest (fractured ribs) and it was assumed that this was a strained muscle associated with playing cricket. His GP finally took the initiative and investigated the condition:

Fred (P 017) "*I used to play a lot of sport, particularly cricket and I kept getting pains down my left side and this went on for years, not months, years, and I kept going back to the GP … and in the end they sent me to the hospital, did a blood test but that showed nothing because really they wasn't looking for anything other than some sort of strain and it went on again for a little while and then in the end my GP said I'm not happy with this. He said I'm going to give you a cardiograph and a full blood test, which I had at* (named hospital) *and within the same day after having it, I came in and there was a message to say would I go back up there because you know that I'd, they'd found out I'd got multiple myeloma*".

Others were more assertive and assumed control from the onset. A phenomenon which has emerged, and is intrinsically linked through 'ways of communication' is 'special knowledge' of an individual who was able to detect a significant change or difference in a loved one (close relative or friend) and the ways in which they were or were not able to articulate these changes. This meant seeing something that the doctor was not able to see even with a 'trained medical eye' except in circumstances where the doctor and patient had a longstanding relationship. Powers of persuasion were therefore required to convince the GP that there was 'something wrong' which ultimately led to

investigating the cause of the problem that might not have otherwise been investigated at that stage.

4.4.2 The analytical story line (Table 3)

It appears that people are driven by stressful circumstances and where normally they would not assert themselves; they take control and become propelled by a force that would not normally exist within them. They become agitated and frustrated which fuels this assertion. The close relationship between mother and daughter (Table 3) was fundamental to the tacit and personal knowledge of a loved one, which sharpened awareness and sensitivity to any subtle change that may go, unnoticed by others. Stella (F 013) who accompanied her daughter (Debs P 009) to the GP's surgery had become dumfounded that apparently the doctor was not going to act on the information she had given him and reacted by confronting him and suggesting that the course of action that he should take would be to send her daughter for a blood test. Stella was able to recognise that her daughter was ill and had been outside the surgery with her for an hour during which time her daughter was vomiting. The GP assumed that the sickness was related to pregnancy and was therefore reluctant to investigate the vomiting episodes. The GP finally agreed to the request for a blood test to appease the patient's mother.

Communicating with the doctor had become critical for Jack (P 014) following previous visits and unsatisfactory outcomes. His condition became steadily worse over a period of months. His father (a doctor) had advised him to ask the GP to arrange to have a specific scan (MRI) and Jack was told that he would have to wait for approximately six months. In desperation Jack decided to take matters into his own hands and arranged to have the problem investigated through private referral. He was subsequently seen by a consultant, and, as a result was diagnosed relatively quickly.

The GP's perspective (John HCP 021) in this trilogy (Table 3) concerns patients who come to the surgery apparently with one aim in mind; which is referral. Alternatively, patients demand some form of investigation regardless of whether they understand what kind of investigation is required and lack the knowledge of

being able to differentiate between various tests or scans and the rationale for undertaking these. Patients and their families are not always able to articulate what the problem is and, as is often the case of someone with multiple myeloma, the onset is usually very non-specific. This means that making any form of referral becomes problematic for the GP because the referral needs to be appropriate. On the other hand evidence suggests that when situations become critical, patients and their families will ask for a specific test because they want action, require answers and want to be taken seriously.

Stella (F 013) – Mother of female patient
"Anyway it was awful, we got this doctor who just, because Debs was pregnant, just said oh more or less patted us on the head and she's pregnant and I, and the next thing was I knew Debs wasn't well really because she allowed me to do this. I wouldn't let it go on as, well aren't you even going to send her for a blood test, you know, in the end, he said I sound as if, you sound as if you're not very happy, and I explained what had happened outside because it was an hour before we got in and Debs was sick and everything like that and in the end he reluctantly agreed to a blood test. He didn't want to give her one, he just"…

Jack (P 014)
"As I'm just not getting any better - back to the GP, back to the GP, back to the GP. Finally, after, several months of this and it just wasn't getting any better, I said to the GP, my dad said get an MRI done, I came back and said to the GP I want an MRI done, just to see what the heck this is and he said yes but you're going to have to wait six months, and I said I can't wait six months, because I was almost bent double at that point, I could barely get to the GP's office, I could barely get anywhere, and it was just absolute agony. I couldn't sleep, I was just in constant pain. So I said give me a list of names of all the bone specialists so I'll go private and try to find out what this is, since you don't know".

Dr. John (HCP 021)
"Some people will come in and they've seen two or three people already and you know that, their mission is for a referral, or their mission is for a scan, whatever that means, and they don't have any idea, they just know themselves, they need something. So often you'd diffuse it by saying OK that, of course that's not a problem but to make a referral to the appropriate person or to ask for the right sort of scan, you need a bit more detail; and actually as you go through things and you spend a bit more time with them, they may get more confidence that you are considering it properly and you're not just fobbing them off" …

Table 3 Communicating with the doctor

4.5 Communicating bad news

4.5.1 The context

Receiving a cancer diagnosis in relation to multiple myeloma may not be the same as receiving bad news concerning a cancer diagnosis per se. The

difference being that multiple myeloma is an incurable cancer. The bad news therefore encompasses two distinct parts, the first being the cancer diagnosis and the second being informed that there is no cure for this particular disease. The time of diagnosis is usually described in terms of 'a shock' for most people and their families (Thomas and Retsas, 1999; Maliski et al, 2002). There are instances when patients and their families are relieved to find out the cause of the illness especially when they have suffered and worried about onsets of recurring infections or unexplained and unresolved bone pain for several months and in some cases years. A 'suspected' cancer diagnosis may be in the forefront of the recipient's thoughts long before haematological referral and final confirmation particularly when there is a family history of cancer. Conversely many are completely traumatised and in a state of bewilderment (Davis, 2002; Persson and Hallberg, 2004). Such trauma is further exacerbated in family circumstances when pregnancy is involved. Debs (P 009) and Mat (F 010) were expecting their second child and they were faced with the decision of having to terminate the pregnancy. This was an extremely distressing life experience which impacted on the whole family. Debs (P 009) was not only trying to come to terms with being diagnosed with multiple myeloma, she had to face the imminent loss of her second child and the ensuing grief.

Events leading up to the breaking of bad or significant news in relation to the diagnosis is varied and complex in this population of patients for example a person may have several bouts of chest infections, rheumatic pain, a history of headaches, nose bleeds or cardiovascular problems. Alternatively an otherwise fit and apparently healthy individual attends the A/E department with a 'suspicious' pathological fracture that has occurred in the absence of a fall or collision. The following extract represents one such case:

Geoff (P 011) "*but on that day I got up just to go out as normal on Saturday; went to play golf with three friends and I hit the ball once on the 5th hole, on the tee shot, and it hurt, quite badly, and finished that hole and then when I hit the ball off the tee on the next hole, which is the 6th hole of the day, the arm just broke, just snapped*".

Some patients are investigated for other potential diseases when abnormalities are detected in routine blood and urine tests. A pre-existing non-cancerous

condition is sometimes diagnosed called monoclonal gammopathy of undetermined significance (MGUS) introduced previously (1.5.3) might transform into multiple myeloma. Patients with MGUS are therefore closely monitored and attend the haematology outpatient clinic for regular blood and urine tests. The knowledge of a 'benign' monoclonal gammopathy or disease can be advantageous as it serves as a prior warning and regular monitoring ensures early detection if and when transformation occurs. Patients may not be familiar with the term MGUS and therefore will not know that it can potentially develop into a haematological malignancy. 'Blood abnormalities' and 'raised protein levels' are common terms used (McRobert 2004) and patients may be satisfied with this level of knowledge and feel reassured with the regular medical checks and routine blood tests. The psychological impact on patients who are familiar with the term MGUS and are aware of implications live with the anxiety of knowing that this could potentially develop into cancer (Rawstron 2005). Patients diagnosed with an asymptomatic or smouldering myeloma, on the other hand are usually aware that it is a matter of time before the disease will progress and treatment is then required. Typically this period of time for the disease to progress is 12-32 months (Bradwell 2006) and psychologically very unsettling for the individual concerned. The following participant describes this period as the "Phoney War" because after receiving the news of her diagnosis she was in relatively good health and her condition remained unchanged:

Sally (P 018) "*I often likened it to, a bit like the phoney war really, that I'd been given devastating news but that actually nothing was happening*".

4.5.2 The analytical story line (Table 4)

Communicating bad news is described as "one of the most difficult responsibilities in the practice of medicine" (Vandekieft 2001:1975). Bad news is defined as "news of life-threatening illness, disability or impending or actual death" (Farrell 1999:101). Doctors have not disclosed all the information to their patients at times when their greater concern has been the detrimental effect the information would have on the patient. Furthermore, Vandekieft (2001:1976) argues, "Physicians do not wish to take hope away from the patient. They may be fearful of the patient's or family's reaction to the news, or uncertain how to deal with an intense emotional response".

Two distinct ways of confirming the diagnosis have emerged from the research data; one approach is the swift onslaught of informing the patient that he/she has an incurable cancer and is likely to die within two to five years but that there is treatment. The second approach is more positive confirming the diagnosis, explaining that multiple myeloma is not curable but that there are treatments and people can live for several years reaffirming that death is not necessarily imminent. The two patients in this (Table 4) trilogy Dave (P 023) and Sally (P 018) had completely different experiences because of the way in which the haematologists approached giving the diagnosis. Nurse Karen's (HCP 022) testimony corroborates the disparity in ways in which consultants approach breaking bad news to patients.

Dave (P 023)
"They gave me a bone marrow biopsy, which is the first bone marrow biopsy I'd ever had and they're pretty unpleasant things, I've had four now, they've all been pretty unpleasant but there you are, and very shortly after that the Haematologist there, a fellow called Dr. Brown who sat me up and said you've got multiple myeloma, you've got about two years to live and we have to admit you straight away, and he pretty much said it in those sort of terms which I appreciated actually. I would rather somebody give you news like that straight, as opposed to weave around with it".

Sally (P 018)
"Gill (Dr) was working at (named hospital) at the time and she did my bone marrow biopsy and we had a long, long chat, and she gave me a lot of encouragement, there was no room for negativity. She gave me an idea of the kind of prognosis, you know that I might have and that made me feel really positive that perhaps I might have 8-10 years of life and I, I left really feeling OK, that I, I wasn't ready to 'pop my clogs' that early and that it was looking at least quite hopeful but I knew at the time it wasn't curable you know that was made quite plain to me. I think it was only after maybe three months or so that Dr. Smith gave me lots of booklets from the IMF (International Myeloma Foundation UK)" ...

Nurse Karen (HCP 022)
"We've got two consultants who are quite different. One would be quite upbeat and quite positive about it, so all they talk about, the fact it's incurable, and you know the fact that you can treat it and you know, you should, you know, and he will talk about patients who've lived a long time and who've survived, he would talk about the long term survivors. We have another consultant who will take the other approach and will talk about the fact that actually, you know it's probably going to kill you in less than five years, and he'll tell you that up front, and I think he's not very good at entering hope".

Table 4 Communicating bad news

4.6 Using complex terminology

4.6.1 The context

Terminology in haematological malignancies is complex and foreign to newly diagnosed patients and their families (McGrath 2001). For healthcare professionals familiar with the language used in haematological oncology, complexity of terms is unproblematic because it has become part of their normal every day vocabulary. Healthcare professionals from other areas of practice and expertise are not familiar with terms such as myelomatosis, paraproteinaemia, plasma cell leukaemia and monoclonal gammopathy all of which may be used in association with multiple myeloma. The majority of malignancies are referred to as cancers for instance, breast cancer, lung cancer and prostate cancer; terms that people are usually familiar with. It is evident from the narrative in Table 5 that communication, information giving and becoming overwhelmed are key issues that have emerged from the data. Problems experienced by the study participants such as doctors communicating in a way that is difficult to understand because of medical jargon, the speed at which it is delivered and the vast quantities of information given are reflected in the literature (Berg and Ahmann 2006, Thomas and Retsas 1999). There are critical points in time throughout the illness trajectory when patients and families are at their most vulnerable. For example having the diagnosis confirmed, during periods of relapse and finally when treatment is discontinued because it is no longer having the desired effect. This crucial point in time was described as "*You're living on 'Death Row'* (Fred P 017). Effective communication and interpersonal skills are of paramount importance especially during times when bad news is given or patients and families are dealing with difficult situations.

4.6.2 The analytical story line (Table 5)

The first extract (Bert P 001) exemplifies difficulty in understanding the terminology used during consultations with healthcare professionals and the speed at which the information is given. The second participant, Bert's wife (Shirley F 002) received a phone call from the GP following medical investigations stating that they were "*going down the myeloma track*" and it was assumed that the recipient of this news fully understood what was being said. Using the telephone may or may not be considered appropriate to convey bad

news such as a potential or actual diagnosis of malignancy. Salander (2002) argues that it should not be dismissed as a way of communicating bad news. Other factors must be taken on board for example how far away people live from the surgery or hospital, the relationship between the family and the doctor and the previous interactions that have taken place. Shirley is a retired nurse and had heard of myeloma but her knowledge was limited. The GP's assumption that she understood the telephone conversation may have been based on prior knowledge of Shirley's past nursing career. As a couple they immediately responded by asking questions in order to understand what was happening.

At the time of diagnosis the majority of patients and family members had heard the words multiple myeloma for the first time. The exceptions are Shirley and one other patient (Phil P 019) whose father had died with multiple myeloma. Using complex and unfamiliar terminology like myeloma represents a common pattern in this study. Primarily patients and their families will ask questions in order to clarify understanding. Some however will need more time before they are able to ask questions, while others misunderstand or think they have heard of the disease before. Mat (F 010) for instance spoke of his reaction when his wife (Debs 009) was admitted to hospital with high blood calcium levels and was informed that she has multiple myeloma:

Mat (F 010) "*when they told her what it was immediately you think oh right I know what it is, in a few weeks maybe we'll get sorted out and everyone will go home.*"

Nurse Jill (HCP 036) in this trilogy (Table 5) discloses her observations during numerous consultations between doctors and patients and implies that the terms malignancy, myeloma and blood condition may be deliberately employed to replace or avoid using the term cancer.

Bert (P 001)
" I have one or two reservations about the health care system and the problem that I think we have largely is that the people who are in charge of such things are very au fait with the detail of the condition and therefore they expect you as a person to pick up the details of that condition very readily and as I've said to one or two people if I spoke as quickly as you do on electronics you would pick up the 10 per cent that I'm picking up from you on myeloma so there is without a doubt a communications problem that is not intentional but because they are so with the detail that it is easy for them to skip through something which to them is mundane and straight forward but to you as the recipient of the information and also the sufferer of the condition who may be suffering very badly and they wouldn't know that.... the communication is not that good I joke seriously when I say you need some training from me on communication skills".

Shirley (F 002) Bert's wife.
"Well the GP rang us at home and I answered the phone and she just said we're going down the myeloma track...just like that... now this was you know following an examination, a meeting and appointment with a general surgeon, a general physician and Dr Smith and it was a surprise he said we'll run some urine tests and we'll do some blood tests and I'll speak to your GP but he gave no indication at all. There is no dire emergency and I've got it written down and I just had an envelope on my lap and I was just writing this down and she said right go to your local hospital and pick up a 24 hour sample and some blood tests and that was it and nobody until we had a telephone call from the GP who said you have been referred to a Haematologist at (named hospital) and that was it and we said why? Do you know it was assumed I feel in retrospect that we knew you know?"

Nurse Jill (HCP 036)
"Well I've been present with lots of different doctors, different consultants and registrars, and have found it quite interesting over the years, and we might see the different ways people, doctors do handle it and manage that situation, and, and also taking into account that each patient, the family of individuals, as well, so there really, there's no real typical scene, I mean, I think, more often than not, I would say the consultant, from consultants level, have not mentioned the word cancer, and have talked around it, have I feel been, quite, not upbeat maybe but have not been as honest as I think they probably could be right at the beginning of the diagnosis and they've always talked about a blood condition. Maybe they use malignancy because sometimes people don't understand what that means, they might say myeloma, which the patient clearly won't understand to begin with".

Table 5 Using complex terminology

4.7 Communicating with children

4.7.1 The context

Communicating with young children was a common theme emerging from the research data. Talking in a way that a child will understand is particularly problematic for parents coping with an incurable cancer as complex, diverse and unpredictable as multiple myeloma. Some parents therefore require help from a healthcare professional to facilitate this communication. Communicating

well with children and helping them to cope with cancer in the family enables them to learn and understand what is going on around them and this prepares them for inevitable changes (Scott et al 2003). Six patients interviewed had children under the age of 12 years. This was highly significant and provided evidence of an increase in younger patients who ultimately have different needs to parents with adult children. The average maternal age is increasing and there is a trend towards older parents (Bray et al 2006, Benzies 2008) which impacts on the additional numbers of patients with younger families. It is known that the majority of patients are over the age of 40 years at diagnosis and that the median age of 63 years has decreased (Schey and Pallister 2004); however it is still perceived as a cancer that affects mainly the elderly. One participant was diagnosed within the first four months of his child's life, which meant that his son had grown and was developing at the same time that the disease was advancing..

Another male patient, Mike, discussed his family support below and stated that his daughter had grown up around his illness. Mike (P 040) was diagnosed in 1993, therefore his daughter was approximately five years of age at the time:

Mike (P 040) "*My wife, my daughter, you know, my sons yeah, two of my sons, they are very supportive really. My daughter you know she grew up around my illness really, because I think she was, she was going to nursery, you know she wasn't that old when I can't remember...She's 19 now, you know*".

Some parents will get to the stage when they feel confident and knowledgeable enough to explain to a child what is happening concerning the illness and treatments. While others simply want their children to have a normal childhood and do not want to cause what they consider to be unnecessary distress. There are those who 'bury their heads in the sand' and appear to be in denial or they do not cope very well themselves with the situation. Dave (P 023) suggested it was unnecessary to inform his children about the disease as they are too young and would not understand:

Dave (P 023) "*Well, so far as the children are concerned, I've simply just not told them. I'm not, I mean they know that, though I'm unwell, on occasions, and I would take a fair amount of pills, and obviously I've given them long lectures of not touching daddy's pills under any circumstances and ...because they are*

intelligent children but they're still too young and they don't know what cancer is, they don't really understand that people get sick and they die, though I mean obviously my father has just died and I don't think they really knew about that but even so I don't see what good it would do, all they need to know really is that daddy gets sick sometimes and daddy takes some medication and keep their hands off medication, that's pretty much all they need to know I think".

4.7.2 The analytical story line (Table 6)

Examples taken from two of the families interviewed illustrate some of the difficulties in communicating with their children in terms of explaining about the illness and its implications in a way that their children will understand. The mother (Debs P 009) demonstrates her little boy's perceptions of his 'mummy's illness'. The child (Ben) is aware that his mother has 'bad legs' and is not able to walk. When his mother went into hospital for high dose chemotherapy and stem cell transplantation to treat the myeloma, she was still not able to walk when she returned home. Ben had understood that his mother was going into hospital to get better and became upset and confused because there was no improvement in her walking. The father (Charlie P 029) on the other hand, recognised that he and his partner needed help to explain to their son about the type of cancer he had and reassure him that his father was receiving treatment and that he was not going to die immediately.

Nurse Claire (HCP 038) describes a family and how they coped with communicating with their child. The mother was able to talk to the child in a language that the child understood. The child was aware of what was happening and therefore was prepared and knew what to expect. This was not a common pattern, however it represents an isolated but powerful account of parents who are able to communicate effectively with their young children and highlights the specific supportive care strategies put in place to meet the emotional needs of this particular child at the most vulnerable time.

Debs (P 009)
"I think the most important one was Ben, our son, who is now three and a half. He was two years old when I was diagnosed so he probably has little or no memory of me having been able to walk Obviously we haven't told him exactly what's wrong with me, so he mainly thinks that it's my hips that are the problem so when I went in (to hospital) for the stem cell transplant and came home, he was very angry that I still couldn't walk. He is looking forward to when I can go out for a walk with him".

Charlie (P 029)
"Mary, my consultant said well because of my son, he didn't really know, he knew I was sick but he didn't know what it was, so that was a problem. I didn't know, we didn't know how to tell him about it...because you know, I've got a good bond with him, so, you know. There was no easy way about it, so Mary, put us on to Joyce (Macmillan nurse). Obviously she's there for, obviously if I'm in pain she can help me ease me pain and that and at the same time she could, you know, talk to me. So in the end she, you know, she spoke to me and Christine (partner). We told him ourselves, in a way where he could understand but he just assumed cancer's, cancer, you're going to die. So we had to explain to him and he's pretty good about it now".

Nurse Claire (HCP 038)
"A lady and her husband, he died on the ward, and they had a little girl of about 4 or 5, and I guess all in the most recent years the girl's memory would be that her daddy had been very, very, very poorly. The wife was very, she knew what she had to do and she had a good relationship, she was very upfront and open and honest, very. So that little girl knew that her daddy was dying and, and knew that he, you know, was very, very poorly and that he wasn't going to get better and when he actually did die, she initially said to me that she, she wondered whether the daughter was going to need some help and support, so we spoke to the health visitor and the health visitor was able to speak to the school but in fact none of that was actually needed and they put her in contact with a local bereavement support they have, you know, sort of counsellors specifically for children but none of that was needed".

Table 6 Communicating with children

4.8 Hidden disclosure

4.8.1 The context

Hidden disclosure and managing the reality of the situation emerged in numerous forms. Making a decision not to tell the children about the cancer as discussed above represents one such form. Glaser and Strauss (1965) use the term "*closed awareness context*" in relation to hidden disclosure and avoidance of speaking to patients dying in hospital about their impending deaths based on the assumption that the news would be too upsetting. Another type found in the data is 'gradual disclosure' especially at the diagnostic stage when one person in the family takes on board more information than the other and decides to retain some of the information for another time. Alternatively a member of the

family will make a decision not to disclose the information because of the potential stress or worry it may create. Diamond (1998) discusses the principle of 'gradual disclosure' which he maintains the majority of doctors practise; although this could be viewed as providing information on 'a need to know' basis. John Diamond surmises: "*In the case of complicated, possibly fatal and emotionally charged illness, never tell the patient more than he is likely to find out for himself, and only ever give* the *best-case scenario*" (Diamond 1998:63).

GPs may well be expected to inform patients of the potential diagnosis and will make a judgement about the amount of detail and possibly anticipate an emotional reaction or anxiety that may ensue by disclosing this information. The first GP interviewed talked about the urgent referral procedure of patients prior to confirmation of a cancer diagnosis and stressed the importance of preparing individuals while not overwhelming them with too much information:

Dr Sam (HCP 020) "*I usually use the word myeloma and then explain part of what it is, and explain that it is a type of cancer. I try not to tell them too much because until a diagnosis is made, I don't really want to overwhelm them and concern them too much. Yeah we do and to be honest a lot of the forms now that we have, asks 'Is the patient aware?' We've got a lot of two week rule forms now for urgent referrals and those always ask is the patient aware that their being referred for possible cancer and I think it's a good idea because especially if they see a specialist and they start talking about cancers that if they're not prepared they're going to go back saying oh my GP never said anything about this so I do pre-warn patients*".

Nason (2004) a journalist aged 45 who had multiple myeloma writes about hidden disclosure and returning to work following recovery from his stem cell transplantation. He did not want people he worked with to know that he had been away in what he describes as the 'world of cancer patients' so he "*invented a cover story*" (p 888) because he felt that if people knew they would treat him differently and thus he would feel more vulnerable. In a previous article Gerson Nason describes how family and close friends were usually very supportive, but it was stressful worrying about whether or not to tell individuals the truth about how he was feeling to avoid upsetting them (Nason 2003).

Several of the participants in the study kept things from their partners or close family members. For example one of the men I interviewed and met for the first

time seemed reluctant for me to come and see him at his home and suggested that I came to the chemotherapy day care unit on his clinic day. He was accompanied by his sister who drove him to the hospital as his wife was at work. Maurice (P 025) was originally from Sierra Leone and in his mid sixties, lived in the UK since 1960 and had two adult sons (ages 26, 31 years) living at home. The interview described previously (Maurice's story 4.2.1) was difficult as he seemed extremely tired and emotional. Maurice appeared unable to talk to his wife and family about his constant bone pain because he perceived this in terms of being a nuisance.

4.8.2 The analytical story line (Table 7)

People find ways of keeping information from their loved ones that is considered detrimental to their well being. The belief is that they are shielding them from harm. The concept of 'protection' emerges from each of these extracts. Alf (F 004) wanting to preserve his wife's positive frame of mind, going to such lengths to avoid having a medical book in the home and telling the family not to disclose the potential 'five year' life expectancy. Shirley (F 002) reading out selective 'bullet points' of information from the website about the disease not wanting to alarm Bert (P 001) or overwhelm him with too much detail. Conflicting emotions are prominent with wanting to know and not wanting to know the full implications of the cancer which is a common pattern in the study. Silvia's (F 028) hidden disclosure was associated with the struggle and worry about finances. She was reluctant to communicate these concerns to her husband thus protecting him from further stress during a difficult period. Each of these family members therefore kept their true feelings hidden and prepared to take on board additional burdens that they themselves found stressful but were not inclined to 'spill the beans' in order to protect their loved ones. In the literature hidden disclosure within the family is addressed in relation to other terminal illnesses (Houldin 2007, Copp and Field 2002). In this research hidden disclosure is described within the context of living with a cancer that is complex and relatively unknown.

Alf (F 004)
"I never had a medical book in the house at Dagenham or here because my sister used to say I've got a lovely medical book, haven't you got a medical book and I said no, we'll have to get one, and we never told her what this, they told us at the hospital. she never knew it was a five year life span she had and I said no she, don't want to know that, we've got her in a frame of mind where she's so positive, I said, I don't know what it would do to her. So the kids never said nothing, I mean we knew it from the social worker, what she told us from the start".

Shirley (F 002)
"I explained to him after reading from the website you know and printing it all off that it was only one per cent of all cancers are myeloma based and when I read I said I'll read you out some of the bullet points Bert and I did - I think I protected him do you know what I mean? I didn't want to go into things that weren't there or say too much because I felt he could take it on board a bit at a time but in point of fact of course it took it out of me because I was still trying to take it all on board Pat and you're numb at first I think - you want to know - you don't want to know - do you know?"

Sylvia (F 028)
"You had all the worry of somebody that could die, plus you had all the worry, and I never used to tell him anything, you know, I used to, he'd say how's things going? I said yeah OK, but I used to try and keep all that side of.. the financial side away from him, because I didn't want him to have to worry about something like that".

Table 7 Hidden disclosure

4.9 Summary

'Ways of communication' was the first of four main categories to be addressed. This was subcategorised into 'communicating with the doctor', 'communicating bad news', 'using complex terminology', 'communicating with children', and 'hidden disclosure' corresponding to the subheadings above. The relationship between *Contention* (core category) and 'ways of communication' is described in terms of difficulties encountered when communicating with other members of the family about the illness or during consultations with healthcare professionals. The next main category is 'Nature of the disease' which is intrinsically linked to ways of communication by rarity, obscure or indistinct onset of multiple myeloma resulting in delayed diagnosis; complicated and unfamiliar language associated with this cancer; complexity and unpredictability of the disease.

4.10 Nature of the disease

"I know that it's just a matter of keep taking stuff to keep it down or find a level that you're happy to live with where either the symptoms, like any maintenance therapy that your on, or symptoms of myeloma itself causing an adverse effect on your wellbeing. I know that's what the disease is so, and I just say give me the next one because I know there will be another one but unfortunately that is the nature of the beast" (Phil P 019).

4.10.1 Introduction

Multiple myeloma may be viewed as the volcanic 'Galapagos' of cancers and unlike any other creating destruction and fragility of the human skeletal and immune systems. The condition is painful and debilitating because of the presence of bone disease which differentiates multiple myeloma from other haematological malignancies or blood cancers. There is a general downward decline which gradually results in a poor quality of health which manifests itself through bone pain, infections, anaemia, fatigue and disability. Quality of life varies considerably. Some people are able to continue with their work and maintain jobs while others are disabled and are unable to do so. The cancer is incurable, difficult to diagnose, difficult to treat and is unrelenting in its progression. The disease is unpredictable with numerous episodes of relapse and remission resulting in instability and uncertainty. The outcome therefore is grim. The rarity, diversity and complexity of the disease lends itself to misgivings and misconceptions. Not all patients want to know or understand the disease that they have while there are others who study the disease, learn about the treatments, have access to websites and keep themselves updated and well informed. Some patients' level of knowledge surpasses that of the healthcare professional. The subcategories that emerged through the 'Nature of the disease' include 'delay in diagnosis', 'living with uncertainty', 'perceptions of the disease', and 'novice to expert patient'.

4.11 Delay in diagnosis

4.11.1 The context

The way in which people communicate with their doctor may have a significant influence on whether or not the initial symptoms are investigated as illustrated above (4.4). Participants were often influenced by others around them for example colleagues at their place of work, family or friends recommending

alternative treatments from therapists such as acupuncturists, osteopaths, physiotherapists and chiropractors:

Jack (P 014)*"In the meantime lots of friends were giving helpful advice about going off to see craniosacral people, and chiropractors and osteopaths, and so I did that route too, I think from people I've talked to, a lot of people went down this route too, and what the devil is wrong with me" ...*

Repeated visits to or from the GP appeared frequently in the data from the first few interviews (5 out of 9) resulting in the decision to interview GPs and explore this issue to establish why multiple myeloma is difficult to diagnose. More importantly why were the GPs treating the symptoms and not investigating the cause? The need to repeatedly visit the GP seeking help regarding a specific problem before a cancer diagnosis is made has been reported by Leydon et al (2003). These authors suggest that difficulties encountered are because of scarce resources especially in deprived areas, additional pressure on the GPs, ten minute consultations, and differences in the GPs in relation to experience and knowledge. An important issue highlighted (Leydon et al 2003) was the type of cancer for example the patients with breast cancer interviewed in this study were relatively satisfied with responses from their GPs immediately prior to diagnosis. This comes as no surprise as breast cancer can be detected more quickly and easily because it is a solid tumour which is palpable and often visible to the naked eye. Other less conspicuous cancers for example leukaemia or myeloma may start out with very non specific symptoms such as mild anaemia or backache. Alternatively the initial symptoms in myeloma can be atypical or obscure causing delay in diagnosis (Bradwell 2006). In the case of a symptomatic myeloma the consequences of a delayed diagnosis will ultimately lead to delayed treatment and disease progression. Dr Ian (HCP 026) disclosed how one of the patients attending his GP surgery finally became diagnosed as a result of obscure symptoms:

Dr Ian (HCP 026) "*She had some rib and thoracic upper spinal pain. I was worried about her, she presented a little bit atypically, well she had those symptoms, plus thyrotoxicosis and I sent her on to a consultant physician, more worried about the thyrotoxicosis. He then went on to refer to a rheumatologist who did a bone scan and actually it took another rheumatologist, after the first one, before the diagnosis came. She actually saw a rheumatologist and think was treated for osteoarthritis plus or minus some bone thinning, before the*

myeloma diagnosis came out. The diagnosis of myeloma came after the rheumatology appointment and was picked up through blood changes rather than bony changes on MRI and X-rays".

4.11.2 The analytical story line (Table 8)

There were two extremes of delay in diagnosis portrayed. The first taking place over a prolonged period of several years (4.4.1) and seemingly non life threatening; while the second was over a shorter period of a few weeks and life threatening. For example admitted to hospital by ambulance in a semi-comatose condition (Pam's story 4.2.1). GPs seeing patients during the first visit make the assumption that they are dealing with something common and thus the notion of a condition that is rare is not considered. A 'strained muscle' is often the assumed diagnosis and a prescription for pain relief appears to be a typical pattern. Subsequent visits to or from the GP have often resulted in the provision of stronger analgesia and referral to a physiotherapist. If the presentation is considered uncommon, abnormal, severe, or there is a family history of cancer it is investigated immediately. The policy regarding common ailments such as muscle strain and backache is to treat symptoms and not investigate the cause which means that the disease, when present, remains undetected and is therefore allowed to progress.

Fred (P 017)
"I kept getting pains down my left side and this went on for years, not months, years, and I kept going back to the GP. They found it out with a blood test but first of all because I was complaining that I'd, I thought it was a muscle because of my sporting days, and things, and it used to, I used to keep getting this, what I thought was a muscle, playing me up, and I went to physiotherapy, I went and nothing ever seemed to happen and in the end that is when I went back to the doctor and they did a blood test but they only did one phial, just a general blood test to see what my general health was like. I mean I wasn't looking for cancer and then as I say then after that I'd had an ... went back again, pestered them and they did a blood test with about 4 or 5 phials of blood, and that's when they found it out".

Pam (P 003)
"Then I went to the doctor and our one wasn't there he was on holiday and the 'fill in' doctor, he just said oh he just didn't even bother to examine me he said you've strained your back he said you got a strained muscle. He said just try resting and that will be OK. So then I went back after a week and I said it isn't getting any better, I said if anything its getting worse, so he just give me another prescription and carried on and then Alf said why don't you have a bed downstairs, save you keep going upstairs, he said, everything's down here you have to get your drink and everything" ...

Dr Sam (HCP 020)
"I think if there's say an abnormal presentation, so if there's a strong family history of cancers, or a strong history of cancers, say the patient had prostate cancer, or had breast cancer and you were thinking of a secondary deposit, you might do an X-ray at that stage. If the symptoms were very severe, so if a sort of simple analgesia or normal analgesia wasn't helping, then you'd do an X-ray. If they've had failed treatment, so if they say that they'd been to a physiotherapist on their own for six months or a year and that hasn't helped, you'd do it then. So but if it's like I started having back pain sort of two weeks ago and it's not getting any better doctor and it goes down my left leg or whatever, then we wouldn't necessarily X-ray at that stage".

Table 8 Delay in diagnosis

4.12 Living with uncertainty

4.12.1 The context

Living with multiple myeloma means surviving with chronic illness that requires continuous monitoring and prolonged periods when lines of chemotherapy are administered with the aim of a partial or complete remission (stable disease). Remission periods typically shorten and the disease becomes refractory or unresponsive to treatment (Durie 2000); a major obstacle being drug resistance (Schey and Pallister 2004). Patients may attend the chemotherapy day care unit or outpatient clinics on a regular basis for monitoring (blood tests) and for other intravenous 'supportive' medication required to treat bone disease

(bisphosphonates), or blood products to replenish low counts such as platelets or red blood cells.

It is not known why some people die relatively quickly while others survive longer. In exceptional cases individuals may live for 20 years or more with the disease. People live with the uncertainty of not knowing how long they will survive; whether or not their current course of chemotherapy is having the desired effect; or how long it might be before they are no longer able to work or pursue normal leisure activities. Coupled with these concerns is an awareness that the disease will not remain stable for long and that relapse is expected although it is not known when this will occur. Living with uncertainty is identified and experienced living with other diseases such as heart failure (Winters 1999), advanced gastrointestinal cancer (Winterling et al 2004), cardiopulmonary disease (Haugh 2005), breast, prostate and colorectal cancer (Shaha et al 2008) and inflammatory bowel disease (Dudley 1995); it is not therefore unique to living with multiple myeloma but the disease prolongs and exacerbates its intensity.

People with other types of cancer live with the 'fear' of potential recurrence. The impact of recurrence of ovarian cancer, for instance, is explicated as "living in limbo" or uncertainty of the future and feeling threatened by the thought of imminent death (Ekwall et al 2007). Recurrence is perceived as a return or reappearance of a cancer that was thought to have been eradicated. People have therefore moved on with their lives thinking that they have 'beaten' the primary cancer and can usually look forward to a future. Relapse, on the other hand, is a progression of disease that exists meaning that a person's condition has deteriorated or worsened sufficiently to require a further course of chemotherapy. The contrast is living with 'repetition of relapse' characteristic of multiple myeloma. Patients often refer to life as a 'roller coaster' because of the 'ups and downs' phenomenon of incurable disease (Carter et al 2004, Nason 2004, Kessler-Berther 2003, McGrath 2001):

Dave (P 023) "*at one point you're feeling relatively healthy, at another point your rather debilitated with chemotherapy, at another point you're popping steroids with their interesting side effects and so on. So that has been the real changes,*

and how you cope with that really is, I mean you have to take a day at a time really, you can't do very much else than that, how do you feel today, what do you need today really. If somebody had for example been in remission for an extended period, I suppose their life is settled to a certain point and then it changed, you might get a different answer but mine's been an exciting roller, medical roller coaster".

4.12.2 The analytical story line (Table 9)

The nature of the disease and living with uncertainty are entwined. Living with multiple myeloma means living with uncertainty. Uncertainty refers to an unforeseeable future and uncharted pathway associated with the unpredictability of the illness (Shaha et el 2008; Bradwell 2006) and its treatment (Schey and Pallister 2004).. Participants speak in terms of 'ups' (positive) and downs (negative) also described as living on a 'roller coaster'. The 'ups' relate to periods of relative normality when the disease is described as stable (remission). There are particular times when participants feel more secure, positive and confident for example when the disease is responding to treatment; or when treatment is still an available option which means death is not an immediate threat. The 'downs' correlate with relapse, which is repetitive and ongoing. Repetition of relapse is frightening, disruptive and unsettling however people learn to cope and become accustomed to these setbacks but they also become reliant on them. Death is a real and immediate threat when the disease becomes unresponsive to treatment and chemotherapy is no longer a viable option.

Frank (P 007)
"It's like living with the sword of Damocles over you all the time. It's like having an albatross around your neck because you know your time on this earth is finite, it's limited and that's the down side. The positive side is that I've had this condition now 4 years. I'm currently on Phase 2 (cycle 2) of the PAD (*PS341, Adriamycin and Dexamethasone) Trial and being optimistic, there's no reason in the world why I shouldn't go on living for another 3, 4, 5 or even beyond years. So, although one has the negative side, there is also the positive side. So it's a mixture of feelings really". *(PS341 was named bortezomib or velcade).

Penny (F 015) Jack's wife
"Just the sort of the ups and downs that you go through with this particular disease, and so you go for, he would go into remission and he would go into a time of relative normality and then he would go out of remission and we'd have to deal with everything again but we got better at dealing with it because we, we'd been through it yeah, so ... and I guess that brings us up to the, the present time which was difficult to deal with too because I guess I got used to the sort of him going into, him relapsing and then, and then going into remission and I thought that would just continue forever and this one looks a lot more serious".

Nurse Fiona (HCP 039)
"As one describes it, it's like a death sentence really, they're looking at a death sentence, they know what's going to get them in the end and so that's something they relate it to. So they're always living with that and I think that has a big impact, not just on the patient but obviously on the relatives as well and the uncertainty of how things are going to happen and how long that life, that line of time really is because they're only given averages and they don't know if their sentence is average or not. So there's all this uncertainty".

Table 9 Living with uncertainty

4.13 Perception of the disease

4.13.1 The context

An individual's perception of the disease from which they are suffering may be entirely different to the perception of close friends and family. A person can look perfectly healthy and normal in appearance and may not choose to talk about the illness or dwell on the topic too much. The consequence of having a 'hidden disease' and apparently looking well on the 'outside' often portrays a false image which can result in misunderstanding and misconceptions about the cancer. Stacey's (1997:138) cultural study of cancer includes two contrasting photographs of herself. In the first picture, she is relaxed, smiling, looking perfectly healthy not realising at the time that she had a "large and potentially lethal tumour" (137); the second picture portrays Jackie Stacey looking like a 'cancer patient' with new hair growth following treatment with chemotherapy. Stacey argues that visions can be deceptive and that people's perceptions of

what they see are interpreted differently. The implication of a deceptive appearance is the assumption that all is well. It may therefore be assumed that everything is fine and no additional support is needed. The following extract reflects this notion illustrating how family members became more concerned when visible manifestations associated with serious side effects from medication were apparent:

Phil (P 019) *"In March she* (ex wife) *and the girls came over and like sorted out my house because I live on my own, as I mentioned for 7 or 8 years. I'd had rooms piled up with junk and all sorts and they helped me basically go through, did it all and now my house is sort of a bit more liveable than it used to be. It was at about the time that I got the DVT* (deep vein thrombosis) *and my daughter had seen this sort of cellulitis, like the thing on my leg and so they were obviously really worried, so it prompted them to do something, because at the time, I was on crutches from the DVT, it was just so painful for about a week, I couldn't even put any pressure on my feet at all, unlike on this leg, so that's what prompted them to finally be a bit more aware that I really was sick. Because that's the other thing, everyone for years, you look great Phil, the fact that I feel like shit, and taking all this medication and having all these side effects that people don't know about"…*

People's behaviour and body language can also belie the true extent of suffering. Patients can be struggling to walk or move with bone pain and severe adverse reactions from medication. They may act normally and be 'themselves' with their loved ones while in the confinement of their homes, however, they often put on a 'show' or act differently in the presence of others. The following extract taken from field notes written during a second visit to validate the research findings exemplifies this:

<u>Field notes 12 October 2007.</u>
<u>P 007, F 008 Study Validation Visit</u>
I told Frank that I thought he was looking well knowing that he is suffering with bone pain. I felt guilty and said I hope this doesn't make you angry. He smiled and said no but you know so many people say this to him. He is almost 70 and has very few age lines around his face. He has a nice face and a good head of hair. Frank stands up straight and appears to walk normally. He said people do not see the 'real me' or do not know what is happening inside. The pain around his ribs, his back, his arms, his legs and people are not aware that he had a morphine patch beneath his jumper sleeve. His legs are so weak that he can only walk a very short distance. Maggie said he is lively and chatting while I am there but as soon as I have left she knows Frank will be quiet and lay on the sofa for hours, and be his 'real self'. Frank has been on a six month trial of revlimid (thalidomide) and he spoke of feeling absolutely wretched while on this medication so much that he wanted to go to bed and not wake up again. Yet he

knows that he may require more treatment and does not realistically expect that he will have too long to wait. For now his disease is stable with an Mband of 9 and he knows this is likely to start creeping up within a few months or less. He is a religious man and he no longer has the energy or the inclination to attend Mass. His faith is very important to him. The saddest thing I heard was Frank has played golf for over 43 years and he is no longer able to play. He loved playing golf. Yet he still has that drive in him and said he was going to visit a friend who was sick and in his eighties so he could cheer him up and make himself feel better!

Family perceptions of a disease that is described to them as an incurable bone marrow cancer is often interpreted as 'dying' and death is likely to occur at any moment. Relatives and friends not seen for a long time appear offering help and support only to withdraw at a later stage when it is realised that the 'patient' is not going to die immediately:

Bill (P 027) "*Everyone sort of rallied round and they were good with financial help. They were there for a little while, and they're sort of, after a while you could almost think, we're still here. Was it as serious as made out? They've all sort of helped us a bit here and there .You felt like a bit of a museum piece at times. Uncles and aunts used to turn up and visit, you know come and have a sit and have a look at you for a little while*".

From a healthcare professional's perspective multiple myeloma is perceived in terms of the "orphan disease" (Dalton 2004) which implies that it has not received the kind of media coverage favoured by other more common cancers such as breast or lung cancers. Perhaps this is not surprising as multiple myeloma represents only 1% of all cancers. In the field of haematological malignancies where it represents the second most common cancer it appears to 'take a back seat' and one of the reasons suggested is association with the elderly. The following extract from a myeloma nurse describes different perceptions relating to 'headline grabbing' leukaemia and apparently uninspiring multiple myeloma:

Nurse Claire (HCP 038) "*Myeloma's not sexy. All the good things that Myeloma UK, it should, raising awareness, all the things like study days today, it still takes a back seat, I don't care what you say. Leukaemia's sexy, leukaemia is headline grabbing. Leukaemia strikes a child and it...myeloma historically, unfortunately, has had a label and I think it still has that label. So it happens to an older population, it happens, doesn't it, and that doesn't grab the headlines as much as a younger population would*".

The following palliative care nurse maintains that misconceptions and misunderstanding surrounding the disease remains. Ellen highlights the point that some people are unable to return to work when treatment has been completed making the comparison between patients with multiple myeloma and patients with other cancers who can resume normal life following treatment:

Nurse Ellen (HCP 032) *"They've still got mobility problems and, you know, they've still got all the difficulties of not working, not mobilising well, not being able to carry on their normal lives, which they're going to be left with, which I think often people aren't so sympathetic with. So I would imagine, although I, I can't say I've had a conversation with anybody recently about this, but I would imagine there's still this misconception, this misunderstanding about the condition and why people can't go back to work once their treatments finished and, you know why they're not, you know, why they can't resume their normal life, like a lot of other patients with cancer problems"...*

4.13.2 The analytical story line (Table 10)

Multiple myeloma is perceived as a cancer that affects mainly the elderly (Kyle 2002). It is acknowledged that there appears to be a rise in the younger patient population (Schey and Pallister 2004). It is also perceived by healthcare professionals as an 'unpopular' cancer that takes a 'back seat' because it is not as 'news headline grabbing' as a child with leukaemia for example. When disability or altered body image is visible, the perception of illness changes and becomes more convincing. People who look well for example are perceived as healthy and the presence of cancer is less believable. The cancer and the language associated with it are complex (McGrath 2001). Patients may have difficulty understanding about the nature of the disease and treatments associated with it because of the complicated terms of reference used. However patients may choose not to acknowledge the condition or deliberately 'block' it out as a way of coping with the situation.

Alice (P 033)
"Really and truly I, I can't understand what's, what's wrong. Just the pain in the back, which I see, I've seen the doctor, with, about the pain in the back. But other than that, I can't, I just can't say. It's, it's in, the pain has been improved".

Val (F 035) Alice's daughter
"Well I mean basically it's, it's a form of bone cancer, and it's to do with the bloods. Mum's had it in, in her back and it's to do with the crushing of also of the spine as well, so the spinal bone it's been crushed, so that's why she walks with a sort of bent. Bent, yea, with a bend, and I mean its terminal. Yea I've got a fair idea of what it entails".

Nurse Lin (HCP 006) ...
"I always think myeloma is very much an old people's disease and it's just one of those things that you get when you get older and ... now it seems that I'm seeing a lot more younger patients with myeloma, lot more aggressive treatments and, and patients with young children and obviously that the fact that a lot of myeloma patients there are issues about mobility for example so it does have a huge impact on their daily life and the family and practicalities of looking after children and sorting out childcare and, and school runs and those sort of issues". ...

Table 10 Perceptions of the disease

4.14 From novice to expert patient

4.14.1 The context

Patients and their family members usually enter the world of haematological oncology 'shattered' by the confirmation of a cancer diagnosis and begin to learn about the hospital environment, the hospital staff, hospital appointments, hospital procedures, the type of treatment that they will have, and gradually may begin the process of familiarising themselves with a new language. The majority of newly diagnosed patients and their family members are in a state of shock, confusion and bewilderment. As novices they are inexperienced and do not have the knowledge or understanding which enables them to ask the right questions or empowers them to take control and make decisions relating to their treatment options and immediate needs. Many of the participants in this study had access to the internet. Patients are usually actively encouraged by healthcare professionals to access the Myeloma UK website for information (www.myelomaonline.org.uk). Myeloma UK registered as a charity in 1997 and provides information, education and support for patients, family members and healthcare professionals.

Patients soon become familiar with terms such as high dose therapy and stem cell transplantation especially if that is their first line of treatment and they need to understand what this entails. Many patients and family members learn the names of various chemotherapy agents and medications some of which are lengthy, complicated and often unpronounceable. The knowledge extends to how the medication acts and reacts to their bodies through the experience of treatment and liaison with healthcare professionals and other patients. Patients and healthcare professionals learn through experience and it can be argued that both parties go through a period of training. The difference is that the healthcare professional training is formalised and structured. Patient expertise is different to a healthcare professional although its value is now recognised as a potentially useful resource (Department of Health 2001). Previously it was not considered relevant.

There are exceptions and not all patients' progress from the novice level satisfied with the confidence they have in the healthcare professionals and relying on them to make decisions on their behalf. Patients and their family members are given volumes of written and verbal information regarding their care and treatment when they attend the outpatient clinics. It is assumed that individuals will read the information when they are ready and when they feel that they are able to cope with the task. There are pharmacy bags similar to any standard sized supermarket edition full of various medications for patients during treatment cycles of chemotherapy waiting to be collected at various intervals when attending the chemotherapy day care unit. A variety of drugs are required for the numerous potential side effects from prescribed chemotherapy; drugs for bone pain, drugs for bone disease and drugs for infections. Patients quickly learn of their susceptibility to infections and may develop a specialised knowledge relating to plasma cells, immunoglobulins (antibodies), neutrophils (white blood cells) and neutropenia (decreased white blood cells). The following abstract refers to a lady talking about waiting for her neutrophil count (white blood cells) to increase sufficiently which would allow her to leave hospital, having had high dose chemotherapy which aims to obliterate the diseased bone marrow prior to stem cell transplant. Unfortunately the high dose chemotherapy

also destroys normal bone marrow resulting in extremely low blood cell counts and virtually no immunity:

Sally (P 018) "*The beginning was fine because I had the, you know, high dosage treatment, I had the Hickman line put in and then the transplant but it was then the waiting. Now the waiting would have been alright ...the waiting for the...what were those blessed, my 'neutrophils'* (white blood cells) *which I nicknamed 'neutropests' because they didn't do what I wanted them to do because you know, they were nought then they'd go up to 2 then they'd go down to 1, all this sort of thing*"

Patients become familiar with procedural terms such as radiotherapy, skeletal survey and bone marrow biopsy. They talk openly about the side effects from the various agents that they have had over the years although there is reluctance to report them at the time of administration because generally patients do not want to have doses of their chemotherapy modified (reduced), delayed or discontinued. Peripheral neuropathy (numbness in the feet and hands) for example is a common term used by patients, a common side effect of velcade or bortezomib and thalidomide. They do not tend to say 'pins and needles' or tingling. Individuals (patients and family members) talk specifically about Bence Jones proteins and paraprotein levels or M Bands and understand these are the markers by which they can assess whether or not the disease is responding to treatment.

4.14.2 The analytical story line (Table 11)

Many assumptions are made regarding language, terminology, perceptions and understanding. As healthcare professionals it is often assumed for instance that patients understand the words haematology and oncology. Most people are familiar with the terms blood and cancer; they have a better understanding of words that are commonly used in everyday language. People living with multiple myeloma have prolonged periods of treatment with chemotherapy agents and some people experience numerous hospitalisations. Many have access to the Internet and vast amounts of information. Some patients will attend education seminars and support groups while others prefer not to do so because they do not want to be reminded of what may happen to them further on down the line by potentially meeting others with a more advanced disease. Patients may develop knowledge through experience of illness and treatment. They may

simply adopt the language communicating with other patients and healthcare professionals within the hospital setting. It is acknowledged that there are individuals who do not study the disease in great detail but it appears many including family members have a good understanding of the cancer and become 'fluent' with the complexity of haemato-oncological terms. The fact that patients learn to use this terminology may be a reflection of the way in which healthcare professionals communicate. Are the patients learning to understand about the illness and management of the disease or are they learning the language in order to communicate more effectively with nurses and doctors?

Phil (P 019)
"Well I know about the different kinds of...not side effects but the way it's detected, through the blood, sometimes through the urine. I mean I've got IgG Kappa so that means that I've got short chains instead of long chains, I think, so there's no urinary detection, apart from possible changes in albumin and stuff like that but I do know exactly how it works and the fact that basically it suppresses... your B-cells are totally non functional because they never mature properly, whether they kick out the IgG or whatever paraprotein that a particular one does, and presuming the IgG is actually used in some form of combatants but it's just on all the time, as the cells mature they just pump it out but the other thing is that they suppress T-cells"...

Frank (P 007)
"Sure, the pain in the upper spine region developed about, I don't know, 16 months ago, something like that and eventually that led to a consultation with a neurosurgeon, Mr. A, and it was decided that having looked at the MRI scans, that a procedure known as balloon kyphoplasty would be appropriate in my particular case and it was agreed to go ahead with that. However, on the morning of the operation, which was January 2005, Mr. A decided that it was going to be too dangerous to get into thoracic 4, where the main tumour was located, so he decided that in my best interests not to proceed with the particular procedure. Now since then, and that's about 15 months ago, the pain level has gradually increased and it's now not only localised around the thoracic region, it's now sort of diffused into the area around the right shoulder blade and the entire ribcage" ...

Debs (P 009)
"We did that with you (clinical trial) for 9 weeks or something and then found out that that hadn't been working, so I had to..., they put me on a new course which was.. I can't remember what I was having now. Thalidomide and Dexamethasone and the Cyclo' ... That's it Cyclophosphamide and that did work and that got my M band right down and then I had the stem cell transplant, my own stem cells and then I was offered the trial for the donor stem cell transplant a few months later. So I've had that and waiting to see if that's worked but I've had to have some extra donor stem cells because the M band was sort of rising, so we're just waiting at the moment to see how that's gone".

Table 11 From novice to expert patient

4.15 Summary

This section of the findings chapter introduced *'Nature of the disease'* which is the second of four main categories relating to the core category of contention. The next main category to be discussed refers to the impact that the cancer has on the lives of the participants. Thus the nature of the disease and impact on life are also intrinsically linked.

4.16 Impact on life

"Still telling me 'I can't see anything'. They sent me back home on a stretcher, tell me to go back and lie down on the floor, it's back pain, yeah. So when my wife couldn't take it again because she actually had to drag me when I went to use the toilet, you know drag me to put me on the toilet and so then drag me back, to lay on the sitting room floor" (Mike P 040).

4.16.1 Introduction

Life was viewed as life before and after the onset of illness. Life as it was known is disrupted and comes to a sudden halt. Disruption occurs in many aspects of life and the impact can be catastrophic. There was the impact of physiological, psychological and socio-economic changes that evolved which might have an immediate impact or develop as the disease progresses depending on circumstances and severity of illness. Multiple myeloma is a cancer that often affects the 'breadwinner' of the family, for example, as the incidence is slightly more prevalent in males and the majority of patients are over the age of 40 at diagnosis. A significant number of the participants (n=11) were not able to continue working because of disability caused by bone disease which creates enormous frustration and anxiety because people struggle to 'make ends meet' particularly when they have been earning a good salary. The shock of the diagnosis had a substantial psychological impact on the whole family. It was an extremely difficult and emotional time for them. Prolonged periods of treatment and healthcare presided over existing working life, family life and social life. For example some of the participants had to cancel booked holidays, which coincided, with the commencement of chemotherapy. Patients and close family members had also, at times, isolated themselves from others (friends or relatives) or avoided contact with people especially when they were susceptible to infection. Relatives for instance were instructed not to visit if they had colds

or influenza. The subcategories that have emerged through 'Impact on life' are 'disrupted life', 'physical impact of disease', 'emotional impact of treatment', physical impact of treatment', 'impact on sexual relationships' and 'impact on family life'.

4.17 Disrupted life

4.17.1 The context

Disruption to life is defined as major upheaval and normal life as known by the participants suddenly coming to an abrupt end (Houldin & Lewis 2006) People living with multiple myeloma who continued to work were are not able to provide the level of commitment that was apparent prior to the onset of illness. Normal working patterns were disrupted due to hospital appointments and treatment regimes. These changes, which inevitably resulted in significant periods of absenteeism, required understanding from working colleagues and a supportive employer, which was not always the case.

Participants in this research also isolated themselves within the working environment and commuted during off peak times to avoid crowded public transportation because of their immunodeficiency:

Geoff (P 011) "*The worst thing, well not the worst thing, is coming to the hospital so often disrupts the working life. I mean I used to work quite long hours from say 8.30 in the morning till 7.00 or 8.00 at night most of the time, five days a week, not any more, not any longer than that but since I've been diagnosed and made so many hospital visits obviously I have taken plenty of time off work and the time I'm at work now because of my immune system is quite often very low, I try to travel out of the rush hour. So I get into the office just after 10.00 now and leave about 3.30, 4.00 o'clock at the latest. I changed, I used to manage the group that I work with now but after going through about a year, I suppose it's just shortly after the high dose treatment, I said to the people in charge I can't really go to meetings and be available as often as I should be I suppose in the role I had, so I basically stepped down from that and let somebody else take over the group, but the company have been very good"...*

Life before the onset of illness was the 'benchmark' that the majority of participants related to. Redefining life comparing with how it was before and reflecting on the consequences is explicated in the literature as 'perceptions of normality' (Carter et al 2004:). Numerous references are made to the life before

and after 'myeloma'. Common expressions such as "*I just want my life back*" (Carol F 012); "*life won't be the same*" (Mat F 010) and "*threw our home life into chaos*" (Penny F 015) are used to articulate the upheaval. The following extract represents a common theme in the data relating to a retired person's full and active life style disrupted by the onset of the disease:

Frank (P 007) *"Life was good, life was full, I had a good full social life. I did the things I wanted to do. I was active; I used to do a little bit of cycling. I played golf regularly, and I was involved in church activities. Life to me before the onset of myeloma was well balanced and full. I had a part time job in a chartered accountants office where I ran the office, I managed things, and I found that demanding but very fulfilling. But then the myeloma was discovered and it completely changed my life from the point of view that I had to finish work at the office, which I did enjoy very much, and I then found that my whole outlook, mental attitude, to life changed, for a period of time – and that was a time of adjustment, to get used to the idea that I had got an incurable cancer - something which was going to, by the law of probabilities, take my life eventually"...*

4.17.2 The analytical story line (Table 12)

Disrupted life means hitting a 'dead stop' and life as it was known potentially undergoing a dramatic and unexpected change. This change means that future plans may be put 'on hold' or destroyed. Numerous examples of destroyed future plans were found in the data. Mat and Debs' plans for the birth of their second child were destroyed along with hopes of Debs returning to her work. Bill and Sylvia did not have any children but enjoyed a 'comfortable life' while Bill was able to work. Bill was self employed and it became a financial struggle for this couple as he was unable to continue with his work because of disability. The third example given in this trilogy from the healthcare professional's perspective (Nurse Ruth) illustrates how the onset of illness and diagnosis of a family member had an emotional and disruptive impact on a family business.

Mat (F 010) Deb's (P 009) husband
"You know both busy with our work, we was sort of whizzing in and out of town to pick Ben up from nursery and so I was leaving at the crack of dawn to get to work so she could leave early and get him and things like that. Busy social life because we had Deb's mum and dad available and so we were still able to go out and socialise and things like that and then all off a sudden, you know, we, already knowing that Debs was pregnant with our second child it was all, everything sort of hit at a dead stop and you were faced, you know faced with a one decision which basically there wasn't two answers to because it was, it was like you're at risk we can hang it out an extra couple of months, however, the baby is very, very unlikely to mature into a sort of a fully developed child or it will have problems even it's born".

Bill (P 027) Sylvia's (F 028) husband
"It has affected us quite a lot because I've not worked since. It's a physical job and I've not been able to work. What happed was I was self-employed but I had just started work with a new company. I'd only been there a couple of weeks. I come straight out from work, I didn't get any sick pay, I didn't get anything. It was a massive upheaval you know, I was earning quite good money and going to work and being comfortable and living your life - and all of a sudden it was a full stop you know. I was out of work; we'd got no money coming in at all and what happen really was that Sylvia was doing all the chasing around to try and get help and they didn't want to know. They kept saying you will have to wait for the doctor and all that sort of thing....it was a massive upheaval at the beginning because we were trying not to get into debt we didn't have a lot put aside, we were really at a full stop"...

Nurse Ruth (HCP 006)
"I've just got a patient, who was newly diagnosed in November and both herself and the husband, they set up a business, this estate agency and everything was planned, and this woman as I say, very, is just like a French lady, very classic woman, very pretty lady, and very, you know, very slim and elegant, blonde lady, with blue eyes, pretty and they are running the business which is in the family. They've got two daughters and one of them is among them, doing the business and suddenly this is what happened, diagnosed, multiple myeloma, of the lady. It really destroyed them and I had to give them sort of like counselling that I was able to give. We had to refer her to counselling people to have a word with her. The palliative care nurses were going to see her. It was really very distressful for the family but now I think she's accepting it".

Table 12 Disrupted life

4.18 Physical impact of disease

4.18.1 The context

The physical impact of the disease is determined by classification of myeloma. For example patients who have the most common type (Kappa or Lambda light chains) IgG (Immunoglobulin G) there appears to be a greater reduction of the normal IgG counterparts, more frequent episodes of infections, a higher serum MBand or paraprotein level, less amyloidosis, less hypercalcaemia and there appears to be slower tumour growth when compared with other types (Foerster 1993). Common clinical features include bone pain, pathological fractures,

anaemia, bone marrow failure, infection resulting from immunodeficiency and renal impairment. One of the most common presentations is back pain of which there were numerous references found in the data. The following represents the physical impact of the disease:

Phil (P 019): "*The year before I was diagnosed I hurt my back, on a fairground ride, I was told it was muscular. When I had my full body scan, I actually had two collapsed vertebrae. Now, my friend Dr Brown is confident that in fact the myeloma has actually softened or affected my spine in some way and this fairground ride just, with the extra pressure, collapsed my spine, which it probably wouldn't have done if I didn't have the myeloma, that's his theory. So that's the only two things, is that I do have lesions and I've got two collapsed vertebrae".*

One of the myeloma nurses interviewed differentiated between leukaemia and multiple myeloma highlighting the disabling impact of the disease and living with chronic bone pain:

Nurse Claire (HCP 038) "*Leukaemia doesn't bring with it the dreadful impact on the daily life in quite the same way. You've still got the diagnosis and the implications of that and what that does to the family but you haven't got that bone pain, the impact, the disabling impact. So, for example, you've got a man in his 50's, you know, bringing in the income, supporting the family and he's reduced to somebody in a wheelchair and he's still got the cancer diagnosis to boot, you don't see that very often do you with leukaemia, it's not painful, the pain presents itself, it's a dreadful thing to live with chronic pain, sometimes no matter how successful the myeloma treatment will be, people are still left with horrible pain, that never goes away, and for me, you see somebody reduced to those sort of states, I think it's a very powerful reminder*"

Less common clinical features of the disease include acute hypercalcaemia when there is an increased level of calcium in the blood causing nausea and vomiting. Symptomatic hyperviscosity is when the consistency of the blood changes due to the increased presence of IgGs and thickens sufficiently to reduce the flow of circulation to vital organs such as the brain, eyes, heart, lungs, kidneys or digits (Foerster 1993); potentially resulting in headaches, confusion, visual and hearing disturbances. Eyes may become 'blood shot' due to retinal haemorrhages, mucosal bleeding may occur from sites such as nose, gums or intestinal tract, loss of consciousness, fatigue, shortness of breath (Hemingway et al 2007) and thrombo-embolic events such as strokes (Perez-Diaz et al 2007). Neuropathies affecting sensation (sensory) and alteration in

muscular tone (motor) may develop in patients with MGUS (Noring et al 1982) and are associated with the presence of paraproteins, osteolytic bone lesions and amyloids (Foerster 1993). Amyloids are waxy deposits of diverse proteins such as light chain immunoglobulins found in organs and tissues gradually resulting in organ failure. Systemic AL Amyloidosis is a primary disease associated with multiple myeloma. AL is the classification for Amyloidosis Light chain. Clinical features are apparent through involvement with the heart, tongue, peripheral nerves and kidneys. The patient may therefore present with heart failure, a swollen tongue with waxy nodular amyloid deposits, peripheral neuropathy or renal failure (Hoffbrand et al 2001).

4.18.2 The analytical story line (Table 13)

The presence of bone disease may be extremely debilitating because of pain and susceptibility to fractures. Other physical symptoms that participants experienced included general fatigue, anaemia, shortness of breath, chest infections, nausea and vomiting, headaches, palpitations and nose bleeds. Dave (P 023) experienced difficulty in breathing when walking up stairs, fatigue, lack of fitness and falling asleep during the day which are common symptoms. Description of the intensity of bone pain is variable. Dave (P 023) implied soreness and stated that his hips felt as if they had been rubbed down with sandpaper which is a stark contrast to Debs (P 009) who was crippled with pain and fractured both her hips trying to walk. Much depends on the advancement of bone disease; the probability of pathological fractures occurring is relatively high especially in an area of bone weakened by the presence of pre-existing disease (Schey and Pallister 2004). The physical impact on Charlie (P 029) was devastating as he spoke of becoming disabled, unable to stand without a surgical back support and crawling up and down the stairs on his hands and knees, not an uncommon experience for patients with multiple myeloma. Geoff (P 011) on the other hand talked of a "*twinge*" in his arm and on the day he played golf and the bone fractured, "*it hurt, quite badly*" implying moderate to severe pain.

Dave (P 023)
"Well, the primary presentation was a sort of pain in the hips but it wasn't like a pain, it was almost like someone had applied sandpaper to the joint, so it was a very odd feeling. I'd never had anything like that before and then obviously my cardiovascular efficiency was well down because of the level of paraproteins. I was getting out of breath walking up the stairs and falling asleep on the sofa and this sort of thing. So it, it was primarily those two presentations. It was the pain in the hips and just the catastrophic lack of fitness, were the main symptoms".

Charlie (P 029)
"Well when I first felt ill, oh I really, you know I, I was frustrated because I thought a slipped disc, was a slipped disc. Then they, it wasn't getting no better, it was just getting slowly worse, I mean I was literally crawling up and down the stairs with my hands and knees, I just couldn't stand up. I was just walking around with a big belt, which if I, when I stood up I had to hold the belt just to support me back and that, so I just couldn't do nothing. So that was frustrating but when I was diagnosed with can' the myeloma, I was a lot happier because at least I knew, obviously it's not a good thing to have but...and at least I knew what was wrong with me"...

Geoff (P 011)
"I had a pain in the upper right arm between the elbow and shoulder and I think I'd actually been to see someone privately about it. I was aware that we had a small car without power steering and if I was turning to the left, as you push the steering wheel over, I'd get a twinge just where the arm actually broke – but on that day I got up just to go out as normal on Saturday went to play golf with three friends and I hit the ball once on the 5th hole, on the tee shot, and it hurt, quite badly, and finished that hole and then when I hit the ball off the tee on the next hole, which is the 6th hole of the day, the arm just broke, just snapped".

Table 13 Physical impact of disease

4.19 Emotional impact of treatment

4.19.1 The context

The emotional or psychological impact is often associated with time and waiting in relation to response to treatment. People need to know that the chemotherapy is working and want constant reassurances that this is the case. Individuals often refer to paraprotein levels or Mbands and understand that these are measurements which determine the success or failure of treatment. Modifications of drug dosage are often necessary because of severe side effects and this ultimately affects response to treatment which can have a massive emotional impact:

Phil (P 019) "*They reduced my dosage to about half and that was both the dexamethasone and the revlimid. The end of my second cycle, I got a DVT; I inject myself everyday with Clexane and then 2 cycles ago I really wanted to have the dosage come back up till I 'plateaued'. Started off with twenty*

something paraprotein in the blood and it went down to 11; it stayed at 11 for like four months, so obviously the dosage was too low, so I wanted to bump it up again. Peter and Kate (consultant haematologists) *were thinking the same thing, so I've had 2 cycles back on full strength, so that was the impact of my most recent stuff and then, my neuropathy is a bit worse now than when I'm not on anything but if I'm not on anything it's still there because of the permanent damage from the velcade*"

A common experience relates to post high dose chemotherapy when patients have their stem cell transplants and must wait for the neutrophil counts (white blood cells) to return to normal before they can be discharged from hospital. The severe side effects from the treatment, the isolation and length of time spent in a hospital room is described as horrendous. The treatment is perceived as one of the most unpleasant hospital experiences:

Dave (P 023) *"I was in hospital about a month with that and the other downside it didn't work desperately well either. It knocked the disease back a bit but, but it came bubbling back of course within a few months. So I went through all of that and it wasn't all that effective. That was probably the most unpleasant hospital experience I've ever had. I was just sort of sitting there thinking I just want this to be over, I want this infection to clear up and I want to be out of here basically and the way it works as you know, is that they measure your neutrophils and when the neutrophils get to 0.5 you get to go OK, you know, and as soon as my neutrophils hit 0.5 I was on the phone to the wife, saying look I can escape get down here as soon as you can because what I didn't want to do was be in another day, phlebotomist turns up takes another blood sample and it drops down to 0.4 or something and I'm stuck back, and then I'm barred from leaving and so when the count didn't come up it was very, very frustrating, it really was".*

It is sometimes necessary for patients to be treated at other hospitals. For those needing emergency orthopaedic surgery for example such as pinning of fractured long bones or kyphoplasty (injection of bone cement), a procedure used in the treatment of vertebral compression fractures. One of the participants in this study had two surgical procedures at a different hospital, which is not unusual, but because of the personal circumstances the emotional impact was catastrophic. The first procedure was termination of pregnancy and the distress experienced by this family was further exacerbated by inappropriate care and apparent lack of compassion. The emotional trauma was still evident several months later when the second procedure (hip replacement) took place. This involved a return visit to the same hospital which was undertaken with dread and reluctance but with resignation:

Debs (P 009) *"When I had to have the termination at* (named hospital) *that was dealt with really insensitively and really badly. It was in a backroom sort of abortion place – it was awful wasn't it?* (looking at husband Mat). *It was really dreadful. Well, I mean I'm sure it was going to be dreadful anyway because of what I was having done but they just ... the doctors came in and they obviously hadn't read the notes and they just were asking, they weren't even asking, they were demanding to know why I was having it and why hadn't I considered having something else, this was like just before, you know while I was there and they seemed to have absolutely no idea or clue as to my background, why I was there and, you know, I was actually having to have it, it wasn't you know, it was my choice but I wouldn't have chosen to have it, had I. not had myeloma but that was just a very bad experience; and it sort of put me off that hospital and I've got to go and have me hips done there".*

Emotional impact associated with waiting for chemotherapy or supportive medication on the day of treatment is also common and described in terms of frustration and irritation because patients feel that the waiting times are sometimes avoidable:

Bert (P 001) "*You have a time set for 9.00 o'clock because the Velcade has a half life of only a small amount of time and invariably you sit there for 2 or 3 hours because the pharmacist can't be bothered to put the stuff together, even though they've known that you're coming for weeks in advance and that really is unforgivable. The same thing applies equally well where I go in for the immunoglobulin infusions. They know I'm coming from one month to the next, they know the day, they know that we will be there at 8.00 o'clock in the morning because they like us to be in there early and we assist in that respect and they are then looking for the doctor to sign off the prescription at ten past nine, which is absolutely crazy, it's just down to bad organisation. The way we did it, was that we would telephone them at 8.00 o'clock in the morning and they would confirm that the blood tests that had been done the previous day, were satisfactory for the Velcade to be given. You know, so there's no real excuse and it's a ten second injection".*

4.19.2 The analytical story line (Table 14)

The emotional or psychological impact of treatment is represented in various forms. Time and waiting play a significant role especially in relation to response and reaction to treatment. Sally (P 018) discussed her experience of being confined to a room day after day, unable to concentrate on anything, "*grounded*" because of infection following high dose chemotherapy and stem cell transplant. Sally stated that she felt as if she were "*going mad*". Shirley (F 002) disclosed how frightening it felt when her husband was taken off all his current medication because of severe liver toxicities. This meant that there was not just the worry

of the disease potentially progressing, prophylaxis (preventive medication) was also withdrawn and the probability of infection reoccurring was high creating feelings of vulnerability, fear and apprehension. Fred's (P 017) emotional experience was associated with his medication which caused him to become short tempered and agitated stating that he "*snaps at people*". The physical side effects from chemotherapy agents causing neuropathy (numbness) in his fingers had resulted in feelings of frustration and angst as Fred was no longer able to do his "buttons up".

Sally (P 018)
"It was the sensation of, I think the high dosage chemo, because what it did was to make all my concentration levels just disappear and it reached the point in the end where I didn't know how I was going to get through a day because the day would be in the room, you know, as if I was grounded because I was, you know I'd got an infection, so I'd have to be in the room all day and I had difficulty in reading, couldn't read. I'd stop... I wanted to listen to my music, couldn't listen to that, put on the television and I couldn't concentrate on that until in the end my concentration had totally gone and ... My last day in hospital, waiting to go home, I was almost out of my head waiting for my friend to come and pick me up. I couldn't sit down, I couldn't, I can't explain it, I just, it was as though I had gone completely off my rocker. I thought my mind was going. I really, really questioned my mentality, because I thought I was going mad ... and it stayed with me when I got home"...

Shirley (F 002)
"It was causing you know, toxicity, he's a mystery man as Dr. Brown called him, only the other day, you're a bit of a mystery why your liver function...So they said that the Dex', the liver likes Dex' and it will relieve the inflammation but it wasn't on this occasion doing this. So of course he hits over the 1,000 which was 'their' level and so they (the haematologists) discontinued it. His M bands were 10 and he stayed at 10 without any medication at all. They took him off the Septrin, the Aciclovir, absolutely everything, with the intent of reintroducing, to see what was upsetting his liver function and his liver function improved quite dramatically, all by itself, with no other medication so he has been having absolutely nothing. So that's been like living on eggshells really, frightened that he'll pick up anything in the way of infection but in point of fact he hasn't"...

Fred (P 017)
"Well I found I become very much more short tempered. I always prided myself on being pretty, kind of, laid back, calm kind of guy really, but I get agitated now and I, and I do believe that is the tablets and I snap at people, I can snap at people, and I never, that wasn't me and I don't like it, I can tell you. I am aware and I just can't help it. You know I get like ... when me fingers are getting a bit funny I even have trouble doing me buttons up and suddenly getting really agitated and you know and that, and I had that going back to me first treatment when I was on vincristine, because that numbs you, as you know but I seem to be able to cope with it OK then but ... oh I suppose it, because it's gone on so long now"....

Table 14 Emotional impact of treatment

4.20 The physical impact of treatment

"*Unfortunately the only treatment that we have for patients with cancer in general and myeloma in particular is extremely toxic with major side-effects to tissues often not affected by the disease itself. This is because the therapy we have is very non-specific and attacks normal as well as the cancerous tissue*" (Marcus in Grummett 2006:3)

4.20.1 The context

The physical impact of treatment is not the same as the physical impact of the disease. The treatment aims to destroy the cancer cells but at the same time the chemotherapy agents also target healthy tissue. Side effects can be so severe that dose modifications are necessary and consequently the treatment becomes less affective. There are newly diagnosed patients who commence chemotherapy with very few symptoms if any from the actual disease and find the side effects from the medication are creating numerous problems and affecting their quality of life. Peripheral neuropathy is a common adverse event associated with treatments such as vincristine, bortezomib (velcade) and thalidomide. Peripheral neuropathy is also associated with the disease but only affects a small percentage of the myeloma population. This side effect may have a massive impact on quality of life and may continue long after treatment has been discontinued and in some cases is irreversible (Richardson et al 2006). Participants in this research (n=4) reported permanent damage to peripheral nerves affecting their hands and feet induced from medication. The following example is a detailed and vivid account of impact on daily living:

Phil (P 019) "*I have to be very careful that if I stand up I'm not going to fall down again, and the other thing is that when I first stand up, I've got to mentally collect myself to gain my balance. Once I'm up I'm OK, because I've been walking for 58 years and it's a totally automatic response but I do need that initial minute or so to get my stability, to get my head round the fact that I can't feel a thing, I don't know if I have my shoes on or off. I remember going out to get in the car and I was barefoot, I didn't even know it. So I have to be careful about stubbing my toes, the same sort of thing problem that diabetics have with their circulation problems. Walking upstairs is a challenge because I got no feedback and I have to be especially careful about the width of the step because on one foot I've got virtually no stability at all. If I'm like near a step I have to be really careful that I get my feet all the way to the back just to give me the extra stability when I'm standing on the step and taking the next step down, and like bumps in the road, kerbs, inclines, I have to use my eyes because my feet don't tell me anything. My feet are totally numb; because my hands are naff, I have big problems with my toenails and not because they're toenails but*

it's the fact that I've got fungal toenails and they're really thick. I have cut them before, cut my toes didn't even feel it, but had blood everywhere".

The high dose melphalan administered as the precursor to the stem cell transplant has both short term and long term associated adverse events. The usual gastrointestinal toxicities were reported such as nausea, vomiting and diarrhoea (short term side effects). A common pattern was a recovery period of several months to a year following the stem cell transplant. Fatigue and weakness was extremely debilitating and discussed in terms of resting on the sofa for a year or not being able to lift the kettle. There is often a reference made to the smell of 'sweetcorn' which is the preservative added to the harvested stem cells that are prepared for the infusion. Ray Grummett reflects on his experience in a hospital lift following his stem cell transplant; the odour exuding from his body was so strong that people were "*asking what the smell was*" (Grummett 2006:36). The next exemplar encompasses common physical side effects of high dose melphalan and the psychological impact of the 'sweetcorn' aroma from the harvested stem cell preservative:

Dave (P 023) *"I had an autograft* (stem cell transplant) *and that was bloody awful, it really was. An autograft means you start off with some pretty unpleasant chemotherapy, melphalan, and that is like being hit with a hammer It really makes you feel terrible, makes you feel nauseous, it gives you diarrhoea, it just makes you feel... you know it's really not a pleasant experience and then the autograft itself, because it makes you smell like sweet corn, you know that? I just really hated that and then of course I caught an infection afterwards, so I was sitting there sort of on two types of antibiotics taking intravenously and so on, and so there I am in a hospital bed, I've got fever, I was feeling terrible, I'd got diarrhoea, the sort of diarrhoea when you're having to dash to the lavatory by the way and you know you're on a drip so you've got to get up and go to the ... and manoeuvre".*

One of the participants spoke of having an allergy to the preservative (not uncommon) and how it affected him on the two occasions that he has had a transplant. The reaction was instantaneous when the infusion of stem cells commenced:

Bill (P 027) "*It's strange and it's instant as soon as they opened the drip and the first little bit went in. It started straight away and it felt like putting a weight on the chest. 'Oh dear I can't breath' and then that panting for breath so they got the old nebulizer, and then more cortisone and more antihistamines and it took a long time*"...

Serious adverse events associated with high dose melphalan such as massive internal bleeding where the stomach lining had been destroyed and cardiac problems such as atrial flutter were also reported (n=1). Hallucinations associated with morphine prescribed for bone pain were experienced by participants (n=2) causing one man, for example, to run out of the hospital dressed in pyjamas afraid that staff were going to murder him. Bisphosphonates such as pamidronate given to treat bone disease and raised calcium levels also have numerous potential side effects, one of which is osteonecrosis or destruction of bone affecting the jaw (Boonyapakorn et al 2007). One participant complained about losing teeth resulting from bone loss in his mouth associated with long-term use of pamidronate.

4.20.2 The analytical story line (Table 15)

The physical impact of treatment is very prominent in the data and emerges frequently. Physical side effects associated with treatment range from minor (mild nausea or small skin rash) to severe (massive haemorrhage or deep vein thrombosis) and may be temporary, permanent or traumatic (invasive procedures such as bone marrow biopsy). Gloria (P 024) described the temporary side effects from the high dose melphalan when she started to vomit a few days following the stem cell transplant. Gloria was unable to get to the toilet because of uncontrollable diarrhoea and had to use a bedpan. Bill (P 027) however had permanent peripheral nerve damage resulting from treatment with bortezomib (velcade). Walking was difficult because of sensory loss; Bill stated "*the toes feel like they're not here*" and disclosed there were various degrees of numbness in his feet, legs and finger tips. Geoff (P 011) referred to the physical and psychological trauma of several months of chemotherapy administered intravenously involving repeated 'stabs' using a special needle known as a trocar and a fine plastic tube or cannula which is inserted and left inside a blood vessel usually in the forearm for the duration of an individual administration.

Bill (P 027)
"As you know the Velcade, that really, that's left me almost completely numb.
I've had to have all tests on that like my feet and leg. I've been back to (named hospital) for tests on all that and they said I've got like sensory nerve damage. So I've got...I'd say the tips of the hands, me fingers are slightly numb but other than that, I've been lucky with that. It's been mainly, it's me toes, the toes feel like they're not there. They're so numb, and the legs, and me feet are numb and then going up, it starts to ease off as it gets towards the knees. I can walk about a little bit but after a little while my feet, like the underside of my feet, I always feel like I'm walking on marbles or golf balls"...

Geoff (P 011)
The cannulations got worse. I come out of here with plasters all up my arms and bruises. That's what I was worried about, really, this last treatment's gone on for, I had 8 cycles, which probably took about 9 months because somewhere along the line I think I had a bit of a delay, and you're having needles stuck in you day after day and sometimes if it's in and you have an hour or so between your blood test and the treatment starting, you go out and have a cup of tea and come back and find its, its come out of the vein and so they try somewhere else, so you're constantly being punctured in your arms and so on, you wonder how long they're going to stand up to any treatment – so it was a bit of a relief actually to get to the end of the 8 cycles and think oh I'll get a break now for a few months hopefully at least".

Gloria (P 024)
"You were in the open ward with the other patients when they give you the chemo, the high dose of chemo, and when they give you the stem cells. But after a few, after about a week, the next week then, you start, you begin to feel this sick symptom, after you have the stem cell, you start to have, I start sicking up, you know, I ain't got much to sick up, just water and drink I was drinking anyway. You start feeling sick so that's when, as you are going to start, the sickness start coming, they move you into a side ward. But on your own because this is when all the immune systems is going down low, and you, you ...I had diarrhoea for about, I started diarrhoea. Think this is when the stem cells ...when they're starting to act and they said the chemicals, is what makes you feel sick and the diarrhoea. I was having diarrhoea so then they had to bring a bedpan"...

Table 15 Physical impact of treatment

4.21 Impact on sexual relationships

4.21.1 The context

Disability or altered body image to do with the disease and its treatment can have a significant impact on sexuality and sexual relationships. A person may be disabled as a result of bone pain, fatigue or may have numerous pathological fractures of the ribcage for example. Significant loss in height associated with multiple myeloma may seem very unattractive. Rupert (1987) for instance was devastated with her altered body image as she gradually shrunk in size losing 10 inches from her original height which she likened to the

severity of losing a breast. Temporary loss of hair associated with high dose chemotherapy and having a bloated appearance due to steroids affects self esteem and body image. It is known that chemotherapy and radiotherapy used in the treatment of haematological malignancies and other cancers can cause injury to reproductive tissue and sexual function (McGrath 2001). There is very little in the literature concerning the emotional impact this may have on individuals and their partners.

The very significant issue of impact on sexual relationships surfaced spontaneously from four participants. Debs (P 009) sent me an e mail following the interview; it was assumed that this was because she was not able to disclose her private thoughts to me in the presence of her husband as they had been interviewed together. This had been in response to the question 'is there anything else you would like to discuss or talk about'? This couple had both, individually, communicated by e mail on several occasions and had said that if they could think of more to say that they felt was important or they had forgotten they would send an e mail in due course. There were two key issues mentioned; the first was the physical act of sexual intercourse which had become impossible because of the excruciating pain due to multiple lytic lesions in the pelvis and fractured hips. The other issue was associated with high dose therapy potentially causing infertility through premature onset of menopause:

(Debs P 009) "*I would have had a very different 18 months if my hips hadn't broken for a start, but they did, and that meant that I have not had sex with my husband in all that time and I am probably starting the menopause because of the high dose melphalan*".

4.21.2 The analytical story line (Table 16)

When people are no longer able to fulfil their sexual desires or needs this has a substantial impact on their lives and that of their partners. Sex is an important part of living but a difficult topic for people to discuss; consequently it is an area that has been largely neglected in the literature. In this research it appeared that individuals wanted and needed to talk about sexual problems. The opportunity to discuss the subject privately on a one to one basis was not always an option because of the presence of others. When interviewing couples, it transpired that

one person wanted to discuss the topic while the other was too embarrassed. One man had a penile tumour and was distraught at the prospect of not being able to satisfy his wife. This was a monumental issue which dominated the interview as it was a subject Mike (P 040) kept returning to. Mike's main concern was the impact this had on his wife and their marriage, which manifested itself through him as constant mental torture and anguish. Participants are aware that the cause of disruption in sexual relationships or sexual activity may be associated with the disease and/or the treatment for the disease. In order to come to terms with this 'loss' there is the tendency to avoid talking about it and therefore avoid dealing with the problem. Frank (P 007), for instance, maintained that sex was no longer a concern and that he tended "*to focus on other things*" implying the need to fill the sexual gap in his life.

Mike (P 040)
"There is difficulties in my life because one time, you know, I find that, you know, my penis had, you know, it had a swelling in the middle of it and then again, you know, I told the doctors and they reckon it's the illness caused this, so there was a breakage in my penis and it became, say may be a quarter of what it was, you know, it became smaller, shorter. The erection of my penis has changed and so yeah my life in that part changed completely because my wife and I didn't use that, you know, we never have contact in that, in that like area. It is a big issue and a big, and a big loss in a marriage really, you know. I mean most, most of the time my wife will say 'Well that's not the only thing that we're married for really', which, it is great to hear your, your wife saying that"...

Phil (P 019)
"I went to my GP and he said yeah it's a bit swollen so then I started going to not proctologist what are they called? What are the prostate people? It's part of the urinary specialists ...yeah, urologists, I went to the urologists and I was on this medication for about six months and I had all these flow tests and stuff like that you know like how loud can you make the tin sound when you're weeing into it, or whatever it is, you know and they stopped the medication, but anyway but all throughout this time, I couldn't have any sex, I mean physically couldn't, you know I had an erectile dysfunction thing, which I now, I still have and so I just don't know how much of that is cross related to my treatment or my condition or, or anything like that but so, that's the only thing really I suppose"...

Frank (P 007)
Well I, lets face it, I lost a testicle. I had, you know, an orchidectomy, the right testicle was removed and that was years ago. I've got the diabetes as well, so all in all I'm completely impotent. I can't, I've no sexual arousal anymore and that's something I've come to terms with, it doesn't bother me anymore. As a young man, I performed well, we've got three children, we had a good compatible sexual life, Mary and myself. Our sexual needs were pretty well similar, you know. Neither one, nor the other had a sort of a rampaging libido, we were absolutely normal in that respect, a couple of times a week perhaps. Now I haven't had sex properly for I guess ten years I don't know what it is but as the years go by you tend to focus on other things.

Table 16 Impact on sexual relationships

4.22 Impact on family life

"Having Ben (son) *around has made things so much better for us to cope with everything as you don't get time to dwell on things. He is so full of life. But I constantly feel terrible for the fact that he will never be able to have a brother or sister. Also not knowing whether I will be around to be there with him growing up"* (Debs P 009).

4.22.1 The context

The emotional impact on the family at the time of diagnosis is catastrophic. Informing family members that a loved one has cancer is extremely upsetting. Informing someone that they have an incurable cancer is also devastating for the individual and the family. The uncertainty of not knowing how long individuals will survive with this cancer means that people are living in disharmony (*Contention*) and are often in a state of feeling 'ill at ease' or unsettled frequently described as 'living on the edge'. People living with the disease for several years experiencing numerous periods of relapse and remission (stable disease) are acutely aware of the potential outcome. They become disillusioned with the knowledge that treatment is not always beneficial and can cause very unpleasant side effects. The following family member spoke in terms of living with a 'bomb' ticking and "living on a knife edge":

Sylvia (P 028) "*It's a ticking thing. Explosion! You're living on a knife edge; you're waiting for blood tests; you're saying oh please God don't let it start rising, the paraproteins, because you know if it starts to rise there's going to be more heavy treatment. So every month when we have to go and have blood tests you sit and wait for the results, hoping and praying that it's never going to like start to rise again. When he had his transplant, the first transplant for a few years it was lovely, you'd wait for the blood tests and they was always low but then two years ago it started to rise again and that started all over again. You know what that's like, well it's horrible because you know what's coming, the transplant, all the treatment, chemotherapy, the trials that don't work but you've got to try them you know because one day please God it will work. It is like living on a knife edge all the time".*

Hospital appointments and prolonged treatment regimes impact on family life and normal routines. For example, arrangements must be made to take the children to and from school; the shopping, washing and other domestic household chores must be attended to. Difficulties arise particularly when couples are working or have additional commitments. Families may suddenly realise that they cannot plan ahead:

Carol (F 012) *"Well it's just uncertainty, isn't it really You just can't, you know all the women I work with go out two times a year and all the rest of it. You just sometimes think to yourself and then they moan and groan about this that and the other. I sometimes think you don't realise how lucky you are just to be able to plan these sort of things. Well I don't think it I say it. You don't realise how lucky you are to just be able to plan these things. I think that's the thing, when this first happened, you kind of spend the first 6 months or so just thinking I just want my life back, just want the life I had, you don't realise how good the life you had was".*

Family life may alter significantly in various ways because of the onset of illness, disability and numerous periods of relapse requiring further chemotherapy. Change in domestic roles in the home where a son or daughter take on the cooking and housework when a mother is unable; a husband may take on the washing and preparation of meals or a wife might take on the chores her husband usually took responsibility for such as sorting out the bills or changing a light bulb when their prospective partners are incapacitated because of illness:

Alice (P 033) *"By that time around six or so, the children, they come in from work, so then you know you've got company and all like that. Then my husband is there, or he's in the kitchen cooking. He's in the kitchen or sometimes he's in the garden, or anything like that, you know. He do the washing. I can go into the thing and switch on the washing machine, or anything like that, where they put the clothes in, and I would switch on but I can't reach the line to hang clothes on"...*

Family members may alter their working patterns or take time off to be with their loved ones who are unwell or having to undergo cycles of chemotherapy or other hospital procedures. In some cases relatives will put their social lives on hold allowing them to be available and provide the support needed at any given time. Although not all families and close relatives live in proximity to one another or are able to provide emotional support or practical help such as taking care of young children:

Stella (F 013) *"I took unpaid leave because although I only worked three days a week and I would have needed just nine days, which I could have done with flexi' and that. They didn't want me to do it flexibly, so I took it unpaid and I just looked after Ben and took him in every day, you know to the hospital and then when Debs had this man's stem cells we took Ben on holiday to France, which was very brave of Debs. I mean I had mixed feelings, I wanted to go with Ben but I didn't want to leave Debs but she booked it and made us do it".*

4.22.2 The analytical story line (Table 17)

Family members do not always see or recognise the severity of a loved one's condition especially when they are in close and continuous contact. Although Marian (F 016) was able to recognise that her mother had deteriorated significantly using her nursing experience and professional judgement, she was not able to convey her true opinion and admit this to other members of her family. Psychological distress appears to be prolonged and intensified for family members particularly during advanced stages of cancer (Dumont et al 2006). Marian's family coped with a difficult situation through a "conspiracy of silence" (Brennan 2004:100) to protect one another from further distress by attempting to minimize the seriousness of the illness (Smith and Cox 2007). Other families recognise the severity of the situation however not all have the luxury of time which allows them to come to terms with the illness and what is happening to them. Jack (P 014) was able to talk openly with his wife and family members and continue to make realistic plans such as moving nearer to relatives where his wife and child would be supported emotionally following his imminent death. The timing of the cancer emerging in relation to age and family circumstances may have a significant bearing on the lives of those involved. Impact on family life and domestic upheaval is exacerbated particularly in families who have young children for example. Loss of identity as a parent and being unable to lift up a child can have a massive impact on individuals causing high levels of anxiety and frustration.

The healthcare professional's perspective Jill (HCP 036) highlights the ongoing and aggressive nature of the cancer and the difficulties families face because of the unpredictability of the disease. The cancer is viewed in terms of a 'time bomb' reflecting the numerous periods of remission (stable disease) and relapse eventually leading to refractory disease, terminal stages of cancer and death.

Marian (F 016) Bereaved daughter
"When she was close to being discharged and her last discharge my aunt had come over from Ireland and you know our aunt's a kind of one of the matriarchs of the family and I really wanted her to come because I knew that mum was really quite sick and I wanted her to be there and she walked in to the room and you know, she just burst into tears because mum looked so awful ...and we couldn't almost see, you know you couldn't always see it as the family because she was skeletal and she just looked like a dying cancer patient but she looked like a dying cancer patient from quite early on. Well, you know my family were always, they didn't always see that, they would just see that, they always looked to me as well to.. if I said mum was feeling, getting better they'd think, they'd believe that, which is fine"...

Jack (P 014) Penny's (F 015) Husband
"May be we would another child, may be we would have – you know, all the maybes, all the things we might have done, aren't going to happen so you just roll with the punches, you know. Things were looking really quite good, Penny's job's going well, everything was going well. So it couldn't have come, really at a worse time. Nathan had just been born, he was four months old, and I couldn't take care of him, I couldn't help take care – and all the way through his growing up there have been times where I haven't been able to help take care of him, or lift him up, and often when I have been able to I can't lift him up now because he is such a big boy but that's been enormously frustrating. So there's finance, there's the raising the children, there's obviously been, you know, just in terms of a relationship, when one partner is ill, that puts a strain on the relationship as well, and then there's the yeah, the money worries too".

Nurse Jill (HCP 036)
"Pre-treatment to end stage so that's a funny time with their ongoing treatment and it's fairly difficult for these patients and families because of all the symptoms and things I've just sort of talked about. They can be, they are ill for a long period of time and they're not ever going to get better or not ever going to be cured, so that has a big psychological impact on these patients and families living with this disease, which is a bit of a, time bomb if you like...and the ups and downs emotionally for them with plateau phases and then proteins going up again and the anxiety of going to hospital appointments after they've had blood tests, what's it going be? and... it just takes over their life really".

Table 17 Impact on family life

4.23 Summary

'Impact on life' introduced above was the third of four main categories which are closely linked to the core category of contention. The final of the four main categories to be addressed is 'Supportive care needs' which is related to 'Impact on life'. It is hypothesised that understanding the impact of multiple myeloma will help to determine the specific supportive care needs of individuals and that of their families.

4.24 Supportive care needs

"I don't think that they (healthcare professionals) *think about the families too much, the social service part of it and, what they have to go through. That sounds very selfish but just to have somebody…a counsellor that actually has the logistical, practical information to help people to arrange their lives around the disease, that would be really helpful"* (Penny F 015).

4.24.1 Introduction

Supportive care is defined as an 'umbrella' term for all services that may be required by patients with cancer and their families at any given point in time before (pre-diagnosis stage), during the illness trajectory and following, the outcome of which may be cure or death and bereavement (NICE 2004). Table 18 includes a list of supportive care strategies and services recommended by NICE (2004) towards improving supportive and palliative care for people with cancer acknowledging the vast disparity in the quality of care throughout the UK.

SUPPORTIVE CARE

- Self help and support
- User involvement
- Information giving
- Psychological support
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- Palliative care (Symptom control)
- End-of-life and bereavement care

Table 18 Strategies and supportive care services (NICE 2004)

Supportive care needs emerged as a main category encompassing numerous ongoing problems and difficulties associated with accessing of services. Some problems were associated with the rarity of multiple myeloma and lack of knowledge relating to the disease. Difficulties experienced by some participants however could apply to people being treated for other cancers, for example, struggling to complete a lengthy and complicated DHSS application form for

incapacity benefit when feeling extremely unwell (Grummett 2006). The subcategories of 'Supportive care needs' include 'invisible struggle', 'impact of policy and 'decision making'.

4.25 Invisible struggle

4.25.1 The context

Invisible struggle refers to difficulties or problems encountered by patients and their family members unseen by the healthcare professionals. Doctors and nurses working in a chemotherapy day care unit for instance tend to focus on patients' immediate physical needs and might not be aware that the journey to the hospital was horrendous or finding a parking space created additional stress. Healthcare professionals may or may not be aware of difficulties relating to other aspects of peoples' lives. It is not uncommon for healthcare professionals to ask patients questions in non-specific ways such as "how are things?" or "how are you getting on?" thus it is often assumed the healthcare professional is referring specifically to their illness or treatment. The patient and family may not perceive the role of nurses or doctors as people who are in positions to help with any problems or concerns pertaining to their situation outside the hospital environment. Patients may not want to disclose financial worries for example with the doctor during a consultation because they may not think that the doctor is able to assist them or offer advice except in medical matters. The following statement emphasises the importance of appropriate assessment and asking the right question:

Karen (HCP 022) *"I have seen some of these patients, I will have seen, on several occasions, and I've not really picked up that there's a particular problem, and it's only when they actually, so I don't think you know, even with the fact that you know I'm a trained ... psychologist that you can so easily miss what is going on in people's lives unless you ask questions specifically, looking at that but we actually just assume it is all OK" ...*

People living with multiple myeloma and participating in clinical trials may travel to hospitals much further away from their homes in order to access treatment regimes involving novel chemotherapy agents that would not be available to them locally. In the present research some people struggled with the trips to and from the hospital for treatment. Others perceived it was imperative that they

were transferred to a hospital that specialised in cancer care regardless of how far away the hospital was:

Carol (F 012) *"I used to live near the Royal Marsden you know you've got to get somewhere like that, you've got to get to a cancer…centre of excellence or, you know somewhere where there's going to be the new drugs".*

Distance was not an issue for all and despite the fact that some of the participants lived within a short distance to the hospital where they were receiving treatment, the journey was problematic because of disability. Practical considerations concerning others especially when family members accompanied a young child created further difficulties and anxiety trying to find somewhere to park the car. Limited parking around the hospital and the costs involved were a constant source of worry. Patients generally do not want to wait around for hospital transport particularly when they are immunodeficient and therefore feeling vulnerable to infection:

Debs (P 009) "*The practicalities of getting to and from the hospital have proved to be one of the most difficult things. It's something that no one gives you information on, you have to work out for yourself and it doesn't just affect the patient, it effects the visitors too, for example getting Ben in to see me when I'm in. There is limited parking at* (named hospital) *and its quite costly, plus the congestion charge, it all adds up if you are coming up every day. I was having to do that too on my first course of chemo coming up 2 or 3 times a week, not knowing exactly how long we are going to be in the hospital, so someone has to keep going out to either move the car or put more money in the meter. It's just another thing making life more difficult than it already is. I'm aware that there is a hospital transport system in operation if you wait for a minibus but it can only support a small number of users and hospital waiting rooms are not the place to be when you have little or no immune system. The same goes for public transport which still has some way to go before the disabled can comfortably assume that they may enter or exit at any given stop".*

4.25.2 The analytical story line (Table 19)

Attempting to access supportive care services particularly when dealing with the DHSS has appeared to be problematic and stressful for many of the participants. Sylvia (F 028) was unable to convince the people at the DHSS office that her husband was extremely ill and incapacitated when applying for financial assistance. The evidence suggests that the staff at the DHSS had not heard of multiple myeloma and would therefore not be aware of the impact, the

consequences or the outcome of the disease. People are not always aware of the benefits or allowances that are available to them. Victor (P 030), for example, had only been in the UK for four years and was unfamiliar with the healthcare system and social services. Not knowing what to do, Victor was relying on the healthcare professionals to anticipate his needs. Fortunately he had access to the internet and was able to search for the information he required.

Insurance companies have been criticised for misleading consumers and suddenly withdrawing cover from patients with cancer at the most vulnerable time (CancerBACUP 2004). The decision to 'pull the plug' regarding insurance cover appears to be activated when the condition is defined as chronic, treatment has failed or the illness is terminal (Pallot 2004). Phil's (P 019) permanent health insurance cover became invalid following his stem cell transplant treatment provided at the expense of the NHS. The support, which Phil had received such as help to clean his house, was no longer there at a time when he was feeling extremely fatigued and unwell coping on his own at home following discharge from hospital.

Sylvia (F 028) Bill's (P 027) wife
"Nine months it took with me fighting and rowing with people to get financial help and thank God we did have our family. Our mortgage was protected for a year so I knew I was alright with the mortgage but it was everything else, council tax, all the different bills. I knew we were getting more and more into debt but as I say we had a good family who were helping us out but the fight with Social Security because they just well you know you've got this illness, it's too bad, they were always pressing him because he was so young in his early 40s and they were looking in books for Myeloma and they mentioned 60s and 70s and they would question well have you really got it you know? They didn't believe us at the beginning. I didn't really know anything and I would look at a text book and when you look in the text book its all 60s and 70 year olds. Even today the 'Bacup Book', they need to update them sort of books because younger people are getting it. They weren't really concerned and when you're getting more and more into debt" .

Victor (P 030)
"You see I don't know the system. I was hoping somebody would tell me what to do and what is necessary. I did search a few things but ... I haven't heard anything. I've just been trying to do things on my own. I applied for housing benefit, ...and I applied to my local council the Borough of Waltham Forest, that's where I am and I've tried that, I've sent that. That, well, they're waiting for some information, from me and my daughter. I've tried to apply for incapacity. I cannot get incapacity because my workplace is to give me statutory sick pay. I've had some problems with my workplace, they've been sending me a lot of... they've been stressing me out and I just decided, well I wasn't going to deal with them. They're stressing me out. They're sending me letters, the company that I work with, they're supposed to be a big company but the way they treat staff, is like, well they're like dirt we're not, we're not cherish' - we're not, you know...not valued".

Phil (P 019)
"The biggest change as well I suppose was, once I had the stem cell treatment, my permanent health insurance no longer covered me, for multiple myeloma, for anything to do with multiple myeloma – because prior to that, they were meeting my travel expenses to London, they paid for a gardener, they paid for my house cleaning and stuff like that, not that I used them very much but you know like I paid my daughter to clean my house and I sent them a bill and they paid it and I had someone do my gardening and they did, they covered all my expenses to here (hospital). Any transplant, this was Cigna (Health Insurance Company), any transplant, of any sort, immediately invalidates the cover for that disease or condition, that's just part of their insurance policy".

Table 19 Invisible struggle

4.26 Impact of policy

4.26.1 The context

During the course of this research participants became aware of the decision taken by NICE to withdraw the availability of bortezomib (velcade) causing a great deal of controversy, alarm and anguish. The reason given was that the treatment was not considered cost effective. Bortezomib (velcade) was however available in Scotland, Wales and Northern Island within the NHS (Martin 2007). Following a well supported campaign led by the Myeloma UK and other cancer

charitable organisations such as CancerBACUP, Leukaemia Care Society and Cancer Research UK, which were instrumental towards a successful appeal, a final appraisal report (July NICE 2007) stated the medication would be available on the NHS for patients in England and Wales following first relapse, having received one prior therapy. This meant that the medication was not going to be an option for patients who had relapsed more than once which was disappointing and misleading when the preliminary recommendations in June (NICE 2007:1.1, www.nice.org.uk) had raised hopes by stating:

"*Bortezomib monotherapy is recommended as an option for the treatment of progressive multiple myeloma in people who have received at least one prior therapy and who have undergone, or are unsuitable for, bone marrow transplantation*"..

The consequences of changing the wording from "people who have received at least one prior therapy" to "people following first relapse" and quantifying this statement with "having received one prior therapy" resulted in a massive psychological blow for many people living with the disease particularly those patients who have had more than one line of therapy:

Sally (P 018) "*This change has radically affected the treatment that I can now expect from my clinicians in that velcade will not be available to me. I believe that NICE have used ambiguous language that did not state clearly what they meant to say/didn't mean to say. This is unacceptable from a body working in the public domain and particularly with vulnerable myeloma patients who had their hopes raised in June only to be completely shattered now*".

4.26.2 The analytical story line (Table 20)

The impact of policy decisions that may determine whether or not a drug is made available that can potentially extend life, on the grounds of whether or not it is considered financially viable, may have devastating consequences for patients with incurable progressive diseases like multiple myeloma. The NHS has been legally bound to provide the finance and resources for treatments recommended by NICE in England and Wales since 2002. The NHS was originally set up in 1948 to provide free healthcare for all and the argument today appears to rest on the area in which people live and a form of rationalisation dependent on cost effectiveness (McVie 2003). Participants

appeared upset and angry at recommendations produced by NICE which meant that many of them would not have access to bortezomib (velcade) within the NHS that could potentially prolong their lives.

Dave (P 023)
"We got this business with Velcade, you know Velcade, where NICE have decided that if you want it, you've got to go to Scotland. I mean what's going on here? This is absolutely absurd, I mean the thing is, it's used for treatment of myeloma, pretty much across the entire rest of the world, except for England and Wales and NICE as, as a body...who are these people? What are they in this authority? They are an absolutely black hole as far as information is concerned. They just issued this pronouncement and obviously as you're well aware the doctors are spitting nails about it, they're absolutely furious about it because of the absurdity of it, and if NICE had trotted out, said this is why, this is the statistical information that we have used to arrive at this, you know, you form a press release, absolute absurdity. I'm beginning to think who these clowns actually are because I haven't much time for them".

Carol (F 012) Geoff's (P 011) wife
"The whole drug's thing is a worry as well really. I mean I'd hate to think you weren't getting, within the NHS, what you should get, because of cost. You read an article that said this, what was it they were going to licence that might be to the detriment of Velcade? (addressing Geoff) It's the breast cancer one. You know, it wouldn't be available, because Health Authorities can't afford it and the whole thing, working in a GP's surgery, very small compared to this but you still realise what a massive waste of money there is in drugs across the board and then people can't get drugs that are going to save their lives. You know, it's just horrendous I think in the NHS. I don't know what the answer is, it's too big. I don't know but it's a worry because you think well supposing you did need something and somebody deemed it too expensive to be available and you can only get it on some kind of a drug trial, which is another reason for being somewhere like this".

Nurse Karen (HCP 022)
"It is very difficult because of all the Velcade issue, in that patients, you know, we had two patients yesterday in clinic who were saying my disease is relapsing slowly now, I don't need treatment now because it's only coming back slowly ... but if I wait for three months when I need treatment, I'm not going to have Velcade, should I have my treatment now, even though I don't need it, and so they're very much of the awareness that actually in three months time is there going to be any treatment option for them because they've done all the others, there's only Velcade, and then thalidomide, which we won't be able to have from this Trust, if NICE turn down Velcade, because they're not allowed to have planning for thalidomide, and those patients are being aware that actually there are drugs out there that could treat them and they can't have them" ...

Table 20 The impact of policy

4.27 Decision making

4.27.1 The context

'*Contention*' in decision-making, relates to the difficulties patients have when confronted with the process of making decisions particularly concerning

treatment options. Some patients do not want this responsibility, while others find their decision making capabilities are weakened as a result of feeling overwhelmed with a vast quantity of information especially when newly diagnosed. '*Contention*' also appears in the form of ethical dilemmas facing the healthcare professional aware that some patients are being influenced by making certain treatment options appear more advantageous than other available options:

Nurse Karen (HCP 022) *"There are some patients who quite categorically right up front say 'I don't want to make a decision doctor, you're the doctor, I want you to decide, I will do whatever you say', and whatever information you give them, they are only ever going to come back to you and say what do you think is best doctor and that's what they'll do. You have other patients who want to know everything, and will go and research it and who will, you know you'll have gone through all the trial options or the other options and giving them lots of information and they'll go off and research it and three weeks later they'll still be trying to make up this decision because they've got so much information. But I'm also aware actually that we have a huge amount of power and that you can get patients to do, depending on how you word it; you can get them to do what you want almost. So if you want somebody to go into the trial, if you make the other options seem less attractive then you can get them to go into the trial. I find that quite scary, that you know, that people are not always given entirely all the information".*

The issue of power and control regarding decision making and influencing patients by suggesting that a particular treatment is, in the healthcare professional's opinion, the best option available was further explored as follows:

R: *Have you been present when a suggestion has been made, by say a consultant when they're influencing or encouraging patients towards a particular treatment, for example, a clinical trial?*

Maura (HCP 037) *Yes, I suppose we do, I mean with drugs like Revlimid because it's so expensive and the PCT's aren't funding it. We have got a trial going on at the moment and so we are saying to patients, well OK we'll apply to the PCT's for Revlimid but I don't think we're going to get it but there is this trial you can go into and that's, and basically that's the only way you're going to get Revlimid.*

Major decisions associated with the illness/treatment that have impacted on the entire family creating emotional upheaval or trauma has been elucidated. Examples that emerged from the data include Deb's (P 009) termination of pregnancy, Jack (P 014) and Penny's (F 015) planned move to Canada from

the UK for much needed family support during advanced stages of the disease and Alf's (F 004) deliberate attempt to protect his wife from the knowledge that she would probably not survive for more than five years. Coping with practical day to day situations such as avoiding contact with others who could potentially infect an individual who was susceptible because of immunodeficiency was dealt with by travelling at off peak times and instructing family members not to visit if they had colds. For example Sylvia (F 028) commented *"We live in a bubble. To build him up I won't let them, no, like I say, obviously you know, but if they've got the slightest sniffle…they don't come in".*

Making decisions regarding travelling and taking holidays proved problematic for many of the participants. Travel by air, for example is not recommended because of the confined space and lack of ventilation on aircrafts; the probability of becoming infected, therefore, is relatively high. Suggestions that passengers are exposed to contaminated air during flights and pilots experiencing ill effects from exposure to fumes (Barnett 2006) have led to the commissioning of a "Cabin Air Sampling Study Functionality Test" by the Department of Transport (Muir et al 2008):

Bert (P 001) *It is frustration more than anything. Not being able to fly because of the chances of infection in the aircraft are quite high and that means that going on holiday, or travelling out of the country is prohibited except, unless you go by boat. It's the circulation or re-circulation of the air in the aircraft. That's where the problem lies, and also the reduced oxygen levels.*

4.27.2 The analytical story line (Table 21)

There are three distinct groups represented here (Table 21). Firstly the minority of participants in this research (n=3) deliberately chose not to study the disease and the management of the illness. Like Maurice (P 025) they distanced themselves from any control or decision-making and were fully compliant allowing the healthcare professionals to take charge. Secondly the majority of participants became knowledgeable about the disease and available treatments, had access to the internet, kept themselves well informed and were able to make well informed decisions like Shirley and Bert were able to do. The third group are at the novice stage and are thus inexperienced patients who are not yet able to understand enough to be able to make an informed decision. It is

not surprising that the consultant is viewed as the expert and therefore is the appropriate person to decide that which is best for the patient in these circumstances. From the healthcare professional's perspective, there is a moral and ethical duty to give the patient and family members all the information available in order for them to make informed choices and understand decisions that are made.

Maurice (P 025)
"I know it was something to do with, with my bones and my bloods but ... all I did was I just go for my treatment and as I say, it was a, it might sound funny and strange but I didn't think it was such a problem, you know. I don't know, I don't know really. As I say, even though the treatment was working and ... I don't know it was, it's very hard to describe isn't it. Even, even though I don't understand why ... I didn't think that I got it but I would go for the treatment, whatever they would say I would do ... so that's, that's the way I've been for, over the years I think. It might sound strange and funny but ...that's the way it is".

Shirley (F 002)
"We've got the time to do a lunchtime break. Say right we'll meet for lunch or meet down at another little place we go to and we can make 2 or 3 hours of it. Do you know what I mean or come back and have a cup of coffee and there's no rush ... but ... you know, we would like to be busier, wouldn't we, we would like to do a lot more travelling, which is what we had planned to do and that's. John (consultant haematologist) said no last year when Bert's paraproteins went up, he said we were going to have to cancel those cruises – and I said well what about the second one because that was 3 months ahead, he said no and he really wanted us to go into the trial just as you were leaving. He would have liked to and we said no we didn't want to come up to London again if we could avoid it. We decided that if this was crunch time, we wanted to be at home and enjoy more of at home, you know".

Nurse Claire (HCP 038)
"They've come to Harry (consultant haematologist) to start treatment and he talks to them, 'Well we can do this, we can do that but there's a third way' and you just tell me what you want me to have and one or two people have actually got quite angry and they've said 'I don't know, you know, you tell me what I should have'. I think sometimes and it's important to give choice, so people can go away and make their own decisions. I'm not saying that isn't but some people, people just, they just want to, 'Please tell me what is the best road and I will go down it' and I can see where they're coming from and I think in this day and age particularly with the Myeloma Nine Trial. So you tell people about that, the do's and the don'ts de-de-de-de and you give them a whole wedge of info' and then you say Oh there is another way you can go down here or you can do this. You can have it here with us, or you can go to your local hospital and you can just, and I'm thinking, ah, and you feel for them, I absolutely feel for them".

Table 21 Decision-making

4.28 Summary

This chapter introduced the core category, main categories and subcategories representing the findings of this research within a framework of contextual and analytical story lines. 'Supportive care needs' was the fourth and final main category to be addressed comprising of three subcategories called 'invisible struggle', 'impact of policy makers' and 'decision making'. The core category '*Contention'* is closely related to '*ways of communication'*, '*nature of disease'*, '*impact on life'* and '*supportive care needs'* which represent all four of the main categories mentioned in this chapter and shown in Figure 5. *Contention* is defined as struggle, battle, disruption and disharmony. These defining characteristics appear to be present during a life crisis such as relapse or disease progression in multiple myeloma.

Contention is linked to the rarity, complexity and unpredictability of the disease. Through ways of communication, for example, *Contention* arises for newly diagnosed patients and their families because of lack of understanding, shock, struggling with complex terminology and a cancer that many are unfamiliar with or have not heard of before. From the GP's perspective there is the struggle of detecting the disease because of its non-specific onset and the fact that it is uncommon. From the patient and family perspective repeated visits to the GP, addressed previously, epitomizes the concept of *Contention*. The model shown in Figure 6 conceptualises the existence of *Contention* (core category) and the relationship with the categories and participant groups. The cell metaphor appearance represents fluidity as the environment is constantly changing as is the nature of the cancer, multiple myeloma, itself. It is unstable and inconsistent. The outer irregular membranous layer represents the erratic and continued pathway of numerous and ongoing periods of relapse and remission (stable disease) characteristic of multiple myeloma.

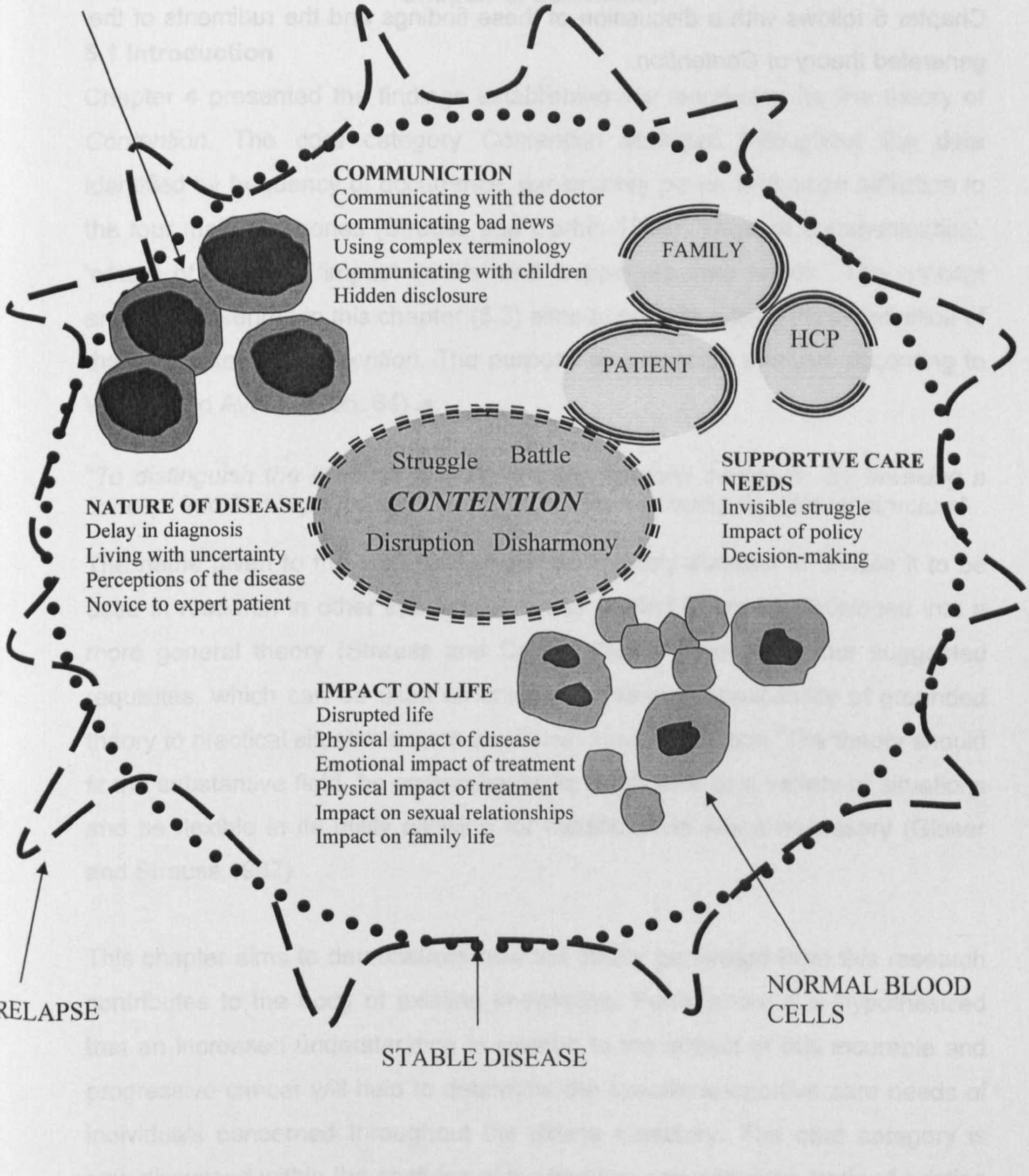


Figure 6 Diagrammatic representation of the core category *Contention*, main categories and subcategories within the context of multiple myeloma.

Chapter 5 follows with a discussion of these findings and the rudiments of the generated theory of *Contention*.

Chapter 5. Discussion

5.1 Introduction

Chapter 4 presented the findings establishing the foundation for the theory of *Contention*. The core category *Contention* emerged throughout the data identified by frequency of occurrence, explanatory power and close affiliation to the four main categories (Strauss and Corbin 1998), 'ways of communication', 'nature of disease', 'impact on life' and 'supportive care needs'. The concept analysis presented in this chapter (5.3) aims to provide a theoretical definition of the core category *Contention*. The purpose of a concept analysis according to Walker and Avant (2005: 64) is:

"*To distinguish the likeness and unlikeness between concepts. By breaking a concept into its simpler elements, it is easier to determine its internal structure*"

The name given to the core category is adequately abstract to enable it to be used in research in other substantive areas so that it can be developed into a more general theory (Strauss and Corbin 1998). There are four suggested requisites, which can be used as criteria to evaluate applicability of grounded theory to practical situations such as clinical nursing practice. The theory should fit the substantive field, be comprehensible, applicable to a variety of situations and be flexible in its utility allowing for modifications when necessary (Glaser and Strauss 1967).

This chapter aims to demonstrate how the theory generated from this research contributes to the body of existing knowledge. Furthermore it is hypothesized that an increased understanding in relation to the impact of this incurable and progressive cancer will help to determine the specific supportive care needs of individuals concerned throughout the illness trajectory. The core category is now discussed within the confines of the findings and within the body of existing literature and current policy. Firstly metaphorical sense of meaning' is addressed, followed by the concept analysis of '*Contention*' in multiple myeloma and its relationship to other chronic or progressive illnesses. *Contention* in communication, *Contention* in the nature of the disease, *Contention* in its impact on life and *Contention* within supportive care needs are discussed. Limitations of the research are also acknowledged. Finally the chapter concludes with

working towards a model of supportive care, summary and emerging overall theory.

5.2 Metaphorical sense of meaning

The aim of using the chosen methodology for this research was to generate theory in an area where limited qualitative research had been undertaken. Thus it was identified as an area of insufficient knowledge and understanding particularly from the patient and family perspective. The theory that emerged from the data should be a true reflection of 'reality' (Strauss and Corbin 1998). Some discussion on the use of metaphors found in the data is pertinent in order to clarify meaning of the core category *Contention* and how it relates to the participants' experiences. The use of metaphorical language enables individuals to articulate experiences, which they find difficult to otherwise explain. Using metaphors is utilization of an alternative phrase, which closely resembles the 'unexplained' literal meaning (Lupton 2003). The fundamental issue here is communicating in a way that patients and healthcare professionals can both understand providing 'common' ground (Penson et al 2004). *Contention* is defined in Webster's Revised Unabridged Dictionary (1998, 1996) as a *violent effort or struggle to obtain, or resist, contest; strife and is synonymous with the following: struggle; strife; contest; quarrel; combat; conflict; feud; litigation; controversy; dissension; variance; disagreement; debate; competition; emulation.*

In relation to metaphors the following is instructive. From Florence Nightingale's endeavours during the Crimean war in British military hospitals the modern nursing profession has advanced from military metaphors of its historical origins. Winslow (1984) argued that nursing was at one time portrayed as part of a battle force against disease and the position held demanded obedience and loyalty to the higher rank of physician. The military metaphor in this context had been superseded by that of the advocacy metaphor strengthening the advancement of nursing as a profession in its own right (Winslow 1984).

Arguments against the rhetorical use of metaphorical language in relation to illness are aimed at demythologizing and demystifying irrational beliefs from the

past (Sontag 1991). Using metaphorical discourse in illness and nursing is criticized as having a "two-edged sword" suggesting ambiguity (Czechmeister 1994). Metaphors may elucidate patients' experiences on one hand, while on the other may provoke negative ramifications such as feeling stigmatized or demoralized. For instance, Sontag (1991:7) postulates:

"*As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have*".

Sontag (1991) proposes that metaphors associated with disease are eradicated and has a particular disliking for military metaphors arguing that the ill human body is not a 'battlefield' and society is not at war with disease. The metaphor of "backfiring" is one of several encountered in Sontag's writing (p 67) referring to 'war on cancer', cancer treatment utilizing colossal amounts of government money and growing pessimism among the medical profession who are viewed upon as:

"battle-weary officers mired down in an interminable colonial war – these are twin distortions in this military rhetoric about cancer" (Sontag 1991:68)

The constant reference to military rhetoric is thus understood as having potentially negative consequences; in other words the other side of the double-edged sword mentioned previously. Others would counteract this argument of attempting to separate metaphorical discourse from illness because it would mean obliteration of the conceptual foundation of common colloquial language and understanding (Lakoff and Johnson 1980; Lakoff 1993). Common verbal expressions used by many of the participants were "*struggle*", "*fight*" and "*battle*" to describe numerous difficulties and concerns (Table 22).

Metaphorical discourse continues to be an established and integrated part of language applied in nursing science such as meta-ethnography and synthesis in qualitative research (Noblit and Hare 1988) and in nursing literature including Stacey's (1997) cultural phenomenon of cancer and Skott's (2002) use of metaphorical expressions in cancer narratives. Table 22 shows fragments of data illustrating common verbal expressions such as battle, fight and struggle

used by patients, family members and healthcare professionals and the **context** in which these expressions were used.

Verbal expression	**Context**
Alf (F 004) "it has always been a struggle"	Hospital trips
Maggie (F 008) "we've got a battle ahead"	Perceptions about surgery
Carol (F 012) "we struggle don't we?"	Travel insurance
Jack (P 014) "I see people struggling"	Hospital trips, finance
Fred (P 017) "I'm struggling a bit"	Side effects from medication
Sally (P 018) "it took a lot of fighting"	Psychiatric referral
Karen (HCP 022) "a lot of them will struggle"	Financial difficulties
Karen (HCP 022) "I struggle with it"	Approaches to bad news
Karen (HCP 022) "patients have struggled"	Taking thalidomide
Dave (P 023) "husband struggling with cancer"	Wife's perception
Ian (HCP 026) "half won the battle"	Reassuring patients
Bill (027) "she did all the fighting"	Financial support
Sylvia (F 028) "he's been fighting for his life"	Internal haemorrhage
Victor (P 030) "it's not a fight".	Misunderstanding
Pauline (HCP 031) "struggling a little bit"	Palliative care referral
Rosemary (F 034) "you've got to always fight"	Staying positive
Jill (HCP 036) "struggle and do too much"	Patients working
Jill (HCP 036) "I have struggled"	Meeting patients' needs
Claire (HCP 038) "he struggles"	Consultant giving bad news
Claire (HCP 038) "see people struggling"	Decision-making (treatment)

Table 22 Use of 'struggle', 'battle' and 'fight' in the data.

5.3 Concept analysis

5.3.1 Introduction

Selecting a concept and determining the purpose of the analysis aims to develop a definition for the term *Contention;* the purpose of which is to clarify the meaning of the concept and its utility. A concept analysis provides an understanding of the attributes, which are intrinsically linked to the concept under investigation. The concept analysis aims to refine and develop terms that specifically relate to nursing language. Clarification of meaning will facilitate development and refinement of emerging theory derived from data collection. *Contention* is considered in relation to struggle, hostility, discord or feuding, (The Collins Thesaurus 1989) between the individual and the disease. The individual relates to the person or persons representing the participating groups

in this study, and the disease is an uncommon form of cancer affecting red bone marrow called multiple myeloma.

Concept analysis involves exploring the relationships between concepts and deciding what it is and what it is not by defining attributes. According to Walker and Avant (2005), if a concept is broken into simple elements it is easier to determine its internal structure. The aim is to describe and examine the term or concept and whether or not it is associated with other words to verify its actual and potential utility with regard to its meaning. Walker and Avant's strategies for theory construction shown in Table 23 provide adequately structured and comprehensible guidelines as the framework selected for the concept analysis. The first and second stages of the framework have already been accounted for - selection of the concept and the aims of the analysis. The third stage is identification of all uses of the concept *Contention;* followed by stages 4 - 8 which include, determining defining attributes; constructing a model case; constructing borderline, related, contrary, invented, and illegitimate cases; identification of antecedents and consequences; and definition of empirical referents.

1. Select a concept
2. Determine the purpose of analysis
3. Identify all uses of the concept
4. Determine the defining attributes
5. Construct cases
6. Identify antecedents and consequences
7. Define empirical referents

Table 23 Framework for concept analysis, Walker and Avant (2007).

The core category in this grounded theory research was something that all the data sources appeared to be confirming. It was seen in every transcript from the patients, the family members and from the healthcare professionals. It appeared to be linked to the rarity and complexity of the disease and took the shape of a struggle, fight, or battle. The core category illustrated previously in Figure 4 represents the central component of an evolving 'category group model' derived from the data in the form of a skeletal rib cage. An example of '*Contention*' is illustrated in the following extract involving the patient's wife who became angry and frustrated dealing with the Social Security personnel. She was unable to convince staff at the Social Security office that her husband had a serious illness and was unable to work. This impacted on close family members who provided financial support during this time. The *Contention* is the "fighting and rowing" that continued for several months:

028 (Family member) 'Contention' in accessing support

"I had a lot of bother at the beginning with finances 9 months it took with me fighting and rowing with people to get financial help and thank God we did have our family and the only thing that did help us at the beginning was that our mortgage 6 months previously our mortgage was protected for a year so I knew I was alright with the mortgage side but it was everything else council tax all the different bills I knew we were getting more and more into debt but as I say we had good family who were helping us out but the fight with Social Security because they just well you know you've got this illness it's too bad they were always pressing him because he was so young in his early 40s and they were looking in books for Myeloma and they mentioned 60s and 70s and *they would question well have you really got it you know – they didn't believe us at the beginning. I didn't really know anything and I would look at a text book and when you look in the text book it's all 60s and 70 year olds – even today like the 'Bacup' Book they need to update them sort of books because younger people are getting it. They weren't really concerned and when you're getting more and more into debt".....*

5.3.2 Uses of the concept *Contention*

The term concept is defined by Meleis (1991:12) as "a label used to describe a phenomenon or a group of phenomena. Concept denotes some degree of classification or categorization". In common every day language a 'bone of contention' is an argument or a dispute. It is a discussion where there is continuing disagreement. The idea stems from a bone thrown to several dogs,

which creates a fight between them (Oxford Dictionary of Idioms 2004). The colloquial use of the term is metaphorical and the phrase 'I have a bone to pick with you' is frequently used at the onset of a disagreement. The term 'a bone to pick' when there is a problem or disagreement has been used since the mid 16th century (Oxford Dictionary of Idioms 2004). Formal use of contention (noun) is seen often and widely used in the literature for example (Osborn et al 2007: 118):

"A major contention of this article is that the lack of progress in reducing alcohol-related harm among college students during the past several decades has been the research community's failure to effectively engage and collaborate with undergraduates on shared concerns".

Walsh's (2007: 26) report in the International section of the Guardian newspaper on fighting between Pakistani tribesmen and foreign militants near the Afghan Border States:

"The Pakistan government claims the revolt is proof that local tribesmen are finally turning against the al-Qaida-linked foreigners, whose presence has been a bone of contention with the US".

In another article (Chatto 2007: 10) in the 'G2' accompaniment of the Guardian a tribute is written for Christopher Lloyd who died in 2006. He authored a gardening column for 17 years:

"However, there was a particular bone of contention: Christopher gave begenias (different to begonias) *short shrift, while I cannot garden without them. These large, and some clusters of smooth, simple leaves, suffused with shades of wine-red in winter, act for me, as a focal point, a full stop to the end of a busy sentence".*

The *Contention of the Bards* (Celtic poets) from Irish literature of early 17th century Gaelic Ireland wrote controversial poetry involving fierce arguments against each other and in support of their patrons. The following verse is from the "Irish Texts Society" (McKenna 1918:185):

"I could say much more but I insist not. I like not that your words force me to speak of such things. From you in the North come the rough words that set folk against each other. You cannot find in your books the name of any of Eibhear's race who swore that oath to forego their ancestral rights. An example that there

were those who took no such oath is Meilge, lughoine's grandson. A king of Eibhear's race took from him his life and the kingship of Eire too!"

5.3.2.1 Dictionary definitions

Contention 1. "Someone's contention is the idea or opinion that they are expressing in an argument or discussion" and exemplifies this with "This evidence supports their contention that the outbreak of violence was prearranged". 2. "If something is a cause of contention, it is a cause of disagreement or argument". For example "a particular source of contention is plans to privatize state run companies". 3. "If you are in contention in a contest, you have a chance of winning it". As in "he was in contention for a place in the European championship squad" (Collins Cobuild Advanced Learners English Dictionary 2003:302). The following example is from The Sunday Telegraph's article on golf (Reason 2007:6):

"But yet again Rose began to pull himself back into contention towards the end of the round. He birdied the 13th and 14th and then showed that Faldo grit when he holed a 20-foot par putt on the 16th".

Contention is defined as "strive, tussle, conflict, clash, running battle, *dissension;* combat, fighting, war, *warfare*; debate, dispute, controversy, polemics, ink slinging, argument; altercation, words, war of words, *quarrel;* bone of contention, competition, rivalry, price war, emulation, *jealousy;* competitiveness, gamesmanship, survival of the fittest, rat race, turf war, cut throat competition, war to the knife, no holds barred, feeding frenzy, sports, athletics, sport, *contest;* trial, trial of strength, marathon, biathlon, triathlon, pentathlon, decathlon, tug-of-war, tug-of-love, *exertion*; tussle, struggle" (Roget's Thesaurus 1987:297).

According to The New Shorter Oxford English Dictionary (1993) Contention is "Strife, verbal controversy, a dispute or a quarrel. Earnest exertion, endeavour, competition, an act of rivalry, or a point contended for an argument". The act of contending (verb) is described as "violent effort or struggle to obtain, resist or compete" (Webster's Third New International Dictionary (1986). Contention City in Arizona was aptly named as a result of unusual rivalry among silver mining

claimants in the early 1880's near Tombstone (Wikipedia the free encyclopedia 2007).http://en.wikipedia.org

Contentious (adjective) is defined as (1) "a contentious issue: *controversial*, disputable, debatable, disputed, open to debate, moot, vexed. (2) A contentious debate: *heated*, vehement, fierce, violent, intense, and impassioned. (3) Contentious people: quarrelsome" (Concise Oxford Thesaurus 2002:170).

Contention is also used in "a situation in which several independent activities simultaneously seek access to the same resource, as when several independent transmitters wish to send data across a single communication channel. Where contention may arise, it is necessary to provide some form of arbitration to determine which activity gains access to the resource" (Oxford Dictionary of Computing 2004:112). An example of this type of contention described as "conflict in requests for the use of system resources" arises when two or more computer users attempt to print items simultaneously from the same printer (Chambers Dictionary of Science and Technology 2002:258).
Sending electronic mail (e-mail) using Broadband Asymmetric Digital Subscriber Lines (ADSL) in the United Kingdom are subject to 'contention' and 'contention ratio'. Contention is the availability of network bandwidth that is shared between several subscribers. The ratio relates to the available shared bandwidth, which means if there are 50 residential users sharing there is a contention ratio of 50-1 (IDNet 1966-2007). The architecture of a computer is made up with a variety of components referred to as buses (White 2006) including pathways along which data are transmitted. 'Bus contention' occurs within the communication control system where a device must wait for a time before transmitting data. 'Contention delay' is the "length of time spent waiting for equipment to become free for use" (Dictionary of information Technology 2002:90). A 'contention resolver' is a "device that enables a central processing unit, memory, or channel whose attention is being requested over several pathways to give its attention to one pathway and ignore all others" (McGraw-Hill Dictionary of Scientific and Technical Terms 2003:473).

5.3.3 Defining attributes

To determine those attributes most frequently associated with the concept involves an exploration of the research data and literature to examine as many of the different examples of the concept as possible. The defining attributes or characteristics may change during the course of development, refinement, applicability and clarification (Walker and Avant 2005). Defining attributes of *Contention* identified in the research data and existing cancer literature are shown in Table 24.

Study data analysis	CONTENTION	Existing Literature
• STRUGGLE, exertion, difficulty, hindrance, negative • BATTLE, fighting, assertion, form of defence, positive • DISRUPTION to life, major upheaval, physical and psycho-social. • DISHARMONY, friction, conflict, discord, inconsistency, ill at ease, alternating.		• STRUGGLE • BATTLE • DISRUPTION • DISHARMONY

Table 24 Attributes derived from data analysis and literature

In the research data there are instances or events where all the defining attributes are present and therefore the concept is easily recognizable. Searching the cancer literature for the concept proved difficult using the search terms *struggle*, *battle*, *disruption*, *disharmony* and *cancer* combined yielded 0 hits. Combining an individual attribute with cancer using the CINAHL database 1982-2007 proved more productive than other databases, which were searched (British Nursing Index, EMBASE Psychiatry 1997-2007, PsycINFO 1806-2007,

Applied Social Service Index and Abstracts (ASSIA), Social Science Citation Index, www.thesis.com). Cancer and struggle (80 hits), battle (86), disruption (108) and disharmony (2). There are instances where one or two of the attributes are presented in the literature but they are not clearly defined. For example struggle and battle are commonly seen in the cancer literature and are used interchangeably. Disruption is a common term used in relation to physiological disfunction that occurs in disease and it also refers to the interruption of normal life patterns as a result of chronic illness. Disharmony is not commonly seen in its written form but its presence is powerful through inference. Conclusions are thus drawn from expressions such as "it's like living with the sword of Damocles over you all the time" (research data). In Grummet's (2006) book '*Myeloma and Me*' numerous statements suggest the presence of disharmony for example, "if they picked up my nervousness" (p13), "the slight unease returned" (p14), "my first uneasy sensation" (p25), "conflicting emotions are at force" (p78), "someone died today, and the atmosphere has physically changed, a pall is hanging over the ward and yet nothing has been spoken to cause this" (p79).

5.3.4 Constructing cases

5.3.4.1 A model case

When all the defining attributes are present, it is referred to by Walker and Avant (2005) as a 'model case' representing a pure example of the concept. A model case can be constructed from real life experiences or examples found in the literature. It is suggested that using a nursing model may distort objectivity concerning the concept and its meanings. The following, therefore, is based on the 'London Bombings' that took place on the 7th July 2005.

Four bombs exploded in London on the 7th July 2005 during the early morning rush hour on three underground trains and a bus. Becoming aware of the first explosion and working in the City was the type of news that made the hair stand out on the back of the neck. As the events unfolded people experienced feelings of shock, fear, confusion, and bewilderment. It became difficult to concentrate on the task at hand. The City was at a standstill. Public transport was crippled due to the closure of the underground system and there were no

buses running. Thousands of people finished work early and were seen walking in London on their way towards home or to the nearest public form of transportation operating outside the affected zone. The atmosphere outside in the street that afternoon was strange, eerie, quiet, and ill at ease. Others that chose not to walk waited at the railway stations. When the train stations reopened there was chaos as passengers ran and pushed to get onto the overcrowding carriages.

The above model case demonstrates 'struggle' in relation to coming to terms with the shocking news. The individual becomes bewildered and unable to concentrate. Therefore it disables the individual. The 'disruption' is the City of London with no transport system. The disharmony is portrayed in the strange atmosphere associated with thousands of 'silent' streetwalkers in the City following the bomb explosions. People at railway stations can, on such occasions, become very aggressive. They tend to fight their way and physically push others to get a space on the train, which exemplifies 'battle'. Thus this model case includes all four of the defining attributes of the concept.

5.3.4.2 A borderline case

A borderline case is one that contains some but not all of the defining attributes. Alternatively this may be an example of the concept where all the defining attributes are present but one attribute may have a significant difference such as an unusual duration or may not appear as frequently when compared to other instances resulting in inconsistency. The inconsistency is the distinction between the model case and the borderline case. The following is also based on the 7th July 2005 London bombings:

The couple sat in front of the television both having finished work for the day with a cup of tea and pleased to be at home together for a change. They were watching the news. They were shocked to hear that there had been a number of explosions in London that morning. Three bombs on the London underground Circle and Piccadilly Line trains had exploded within seconds of each other. Then about an hour later the roof was blown clean away from a double-decker bus while travelling through Tavistock Square. People had been killed or

seriously wounded. It was difficult to get their heads around what was happening and they stared at one another both thinking the same thoughts and immediately feeling very unsettled. London was like a war zone and their only child may be caught up in it all. Their daughter traveled on the underground to get to work. They started to worry and were frantically looking for her new mobile number when the house phone rang. It was their daughter to let them know that she was alright. She had traveled on the earlier train heading for Russell Square and she was fine. They were not to worry.

The above borderline case demonstrates some but not all of the defining attributes. There is the 'struggle' to come to terms with the shocking events as seen in the model case. Disharmony exists in the sense of feeling unsettled and the urgent need to contact their daughter to make sure she was safe. There is an element of disruption to their evening while watching the television and relaxing. The disruption to their evening is minimal in comparison to the disruption in the model case, which is major and catastrophic. There is no evidence of a battle taking place.

5.3.4.3 A related case

Related cases are those concepts that are considered to be similar or closely associated to the concept under investigation. Related cases require close scrutiny to find the differences between them and they do not contain all the defining attributes. Related cases help to clarify individual concepts and to establish their unique identities. The aim is to understand how the "concept being studied fits into the network of concepts surrounding it" (Walker and Avant 2005:71) The concept *assertion* will be considered as a related case. Assertion (noun) is a positive statement or the act of asserting. To assert (verb) means to speak and act forcefully for example to insist upon one's rights. Being assertive (adjective) is being confident and direct in dealing with others (Collins English Dictionary 2001). The following represents the related case and illustrates the assertiveness of Sally Kane's General Practitioner (GP) who she visits prior to having major surgery for breast cancer. She was desperate to talk to someone and speaks of cancer patients and the *"terrifying speed with which they were*

swept on to the cancer conveyer belt – leaving no time for calm consideration or a second opinion" (Kane and Kane 2002:223):

"At five o clock on a Friday afternoon, and with two and a half days before my scheduled operation, I sat in Dr Joy's surgery, pouring out all my concerns. She halted me right there, pointing out that it was unnecessary to proceed at such haste, when certain issues about the reconstruction were so unclear. A few days would make absolutely no difference to my health and safety. With that she grabbed the telephone and made two fundamentally important calls. She called my surgeon's clinic and cancelled my surgery on the Monday, until further notice. Then she arranged for me to see another plastic surgeon at 08.00 on the Monday morning" (Kane and Kane 2002:223).

The concept assertion is similar to contention when there is disagreement or some kind of dispute. The subtle difference is the approach and level of forcefulness. Being assertive is successfully negotiating with others while disagreement or dispute is often associated with anger and aggression. The exception would be a scholarly debate where one team will argue from one perspective while another team counteracts the argument with a different point of view. The related case contains only one of the defining attributes (struggle), which relates to the sentence *"pouring out all my concerns"* and is associated with the fact that things were happening at such a fast pace for Sally who needed to talk to her doctor. Sally required more time to think, come to terms with what was happening, and make more informed choices regarding the reconstruction of her breast. Her GP's assertiveness allowed her this opportunity.

5.3.4.4 A contrary case

A contrary case is a complete contrast to the concept being examined. It is therefore definitely not an example of the concept thus it is something completely different. Identifying that something is without doubt not an example of the concept will help to establish that which is. The complete absence of all defining attributes determines essentially that it is not an example of the concept. A complete contrast to the 7th July 2005 London bombings was seen the day before on the 6th July when it was announced that London had won the bid to host the 2012 Olympic Games: London, on that day, had a 'balloons and

party' atmosphere: Crowds of people gathered in Trafalgar Square jumping up and down cheering with excitement and jubilation.

5.3.4.5 An invented case

An invented case is a way of seeing something that is very familiar outside its normal domain. To invent a case involves something imaginary, which is alien so that it might actually read like a science fiction. Walker and Avant advocate that to get a "true picture of the critical defining attributes, you must take the concept out of its ordinary context and put it into an invented one" (2005:72) which is illustrated below:

They came in their millions (micro-organisms) all shapes and sizes from the air and earth. The first team landed on the moist, uneven, quivering and bushy surface. They found the entrance camouflaged by sticky twigs. Many had difficulty getting through and were unable to pass into the red area where most of the fighting was going on. Those who were not successful proceeded to find another entry. The resistance was strong and some of them were destroyed by the large hot wave of solution that appeared suddenly forcing them away from the target and into oblivion. The survivors soldiered on determined to reach the place where the invasion had begun. On arrival they appeared to have multiplied in numbers and taken over the entire field. It was an easy war. They were the conquerors and they settled in to enjoy their spoils. They remained there for a prolonged period of time. They liked the red area. The climate was perfect to live and breed and so they continued to flourish. Gradually things started to change. Slowly the atmosphere and surroundings took on a menacing new contour. Boundaries were shifting and the colour had changed from red to orange. The 'settlers' did not like these unexpected changes and they started to feel perplexed and a little edgy. They did not understand what was happening to them. This was not something they had anticipated. Their equilibrium was being seriously threatened. Without warning one entire group completely vanished resulting in total chaos and disorganization from within the whole colony.

The invented case demonstrates all of the defining attributes. The struggle applies to the difficulty in gaining entrance. The battle is their determination to

find another solution and soldier on. The disharmony is the imbalance in the 'settlers' equilibrium as a result of the unwelcome changes occurring around them. The disruption is the sudden chaos and disorganization that occurs when a group unexplainably disappears.

5.3.4.6 An illegitimate case

An illegitimate case demonstrates improper use of the concept or it is used out of context. Bus contention that occurs in a computer for example only contains the attribute disruption, which is minimal and does not contain the remaining critical defining attributes of struggle, battle, and disharmony. Therefore this would not be applicable or appropriately used within the context of living with an incurable and progressive disease such as multiple myeloma. An example of an illegitimate case follows:

The young man sat in front of his computer at home trying to access Broadband. The usual notice appeared to inform him that he had failed to do so and would he 'please try again later'. He grumbled, as he wanted to send e-mail before he went out. It was Sunday and he was playing football. He made a comment to his brother regarding the fact that other users were probably to blame for the inconvenience stating "I guess our contention ratio is 100-1 and they are all using the line right now."

5.3.5 Identifying antecedents and consequences

This stage of the analysis helps in the clarification of the concept in relation to its general applicability and further refinement of critical attributes. Antecedents are situations occurring prior to the event of the concept emergence. Consequences are outcomes or factors that are produced as a result of the concept appearing thus they occur following the event of the concept. With reference to the research data, the antecedents, which precipitate *Contention* in living with multiple myeloma, are:

- Onset of illness
- Cancer diagnosis
- Communication issues

- Accessing support
- Experience of treatment
- Impact on life
- Making decisions and plans
- Uncertainty
- Unrelenting nature of the disease
- Time and waiting
- Relapse and remission

The consequences are alterations and adaptations. Alterations are of two kinds and relate to life style and physiological or body changes. Life changes as a direct result of the presence of disease and treating the illness. Receiving treatment can mean frequent trips to the hospital for chemotherapy and blood transfusions. This often involves seeing specialists at other hospitals, which are further away. The resulting far-reaching implications have a significant impact on daily life. When the breadwinner in the family is taken ill and is no longer physically fit to continue to earn a living, this can lead to all sorts of problems associated with financial loss and struggling to support the family. The body is altered because of the presence of bone disease and also as a result of side effects from medication. Adaptations are the ways in which people adjust and learn to cope living with the disease. It also concerns how individuals manage and become more knowledgeable about the condition. Figure 7 illustrates the relationships between the antecedents, defining attributes and consequences.

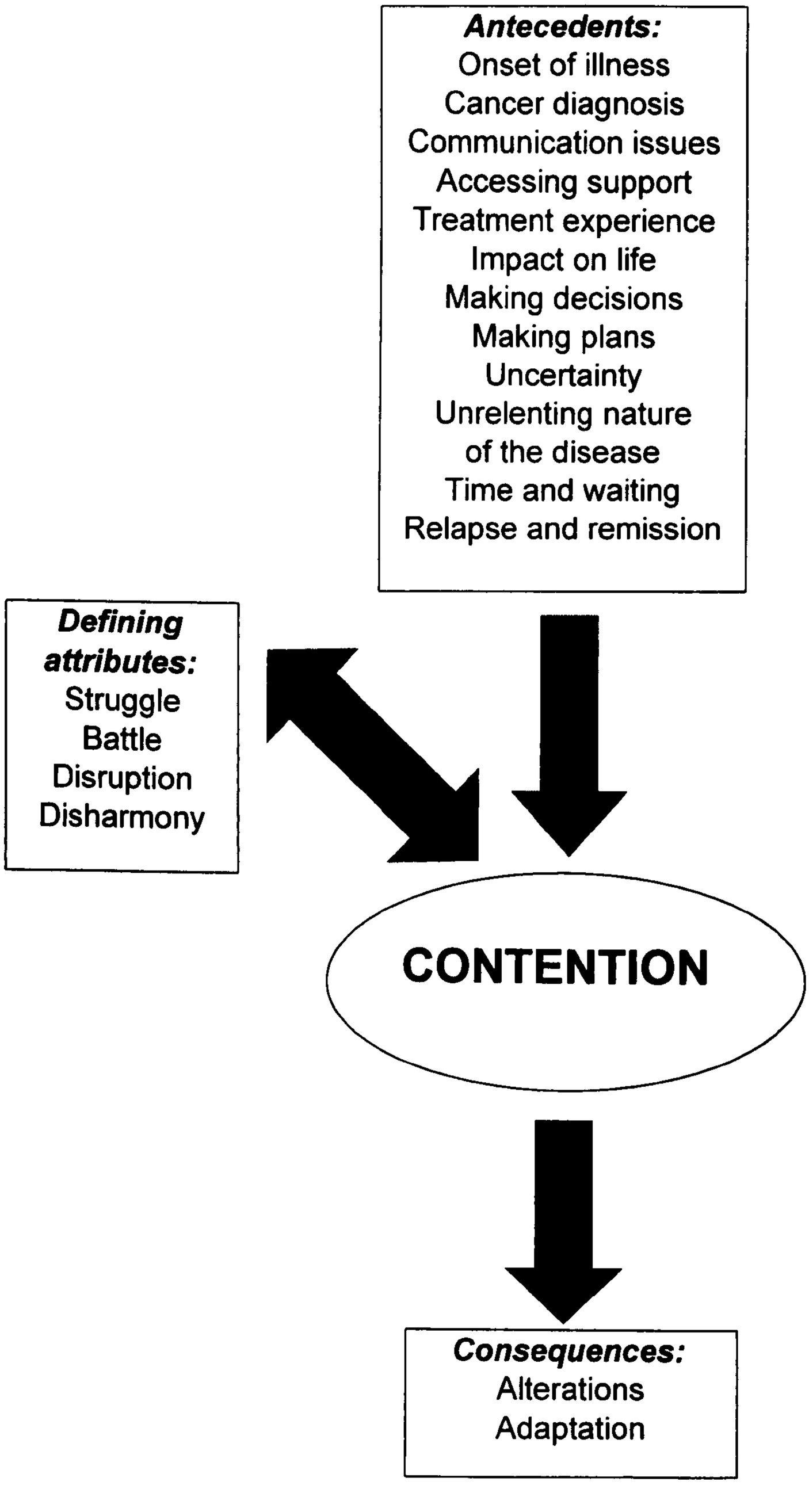


Figure 7 Antecedents, defining attributes and consequences of *Contention*

5.3.6 Defining empirical referents

Empirical referents are the observable indicators linked to the concept that may be identical to the critical attributes and which determine characterization of phenomena establishing recognition of the concept and proof of its existence (Walker and Avant 2005). Empirical referents such as patient behavioural patterns, actions, reactions, verbal expressions, and nursing observations serve as valuable criteria on which to base assessment and identify an individual patient's problems (formation of diagnoses) in nursing practice. It is not always possible to measure empirical referents associated with concepts such as struggle, battle, disharmony and disruption due to their level of abstraction. Qualitative research provides a way of producing evidence of their existence. Table 25 displays the empirical referents of *Contention* under five headings: behavioural patterns, verbal expressions, socio-economic, psychological, and physiological changes.

Behavioural patterns	**Verbal expressions**	**Socio-economic changes**	**Psychological changes**	**Physiological changes**
Anger Frustration Fear Panic Dread Worry Anxiety Restless Hyperactive Tearful Tense Distress Nervous Ill at ease Overwhelmed Apprehensive Withdrawn Depressed Denial Positive Negative Jocular Assertive Disillusion	An irritable monster. Disabled/ cannot work. Alarm bells. The sword of Damocles over you. Running out of options. Living on Death row. Fear of infections. Panic attacks Dread of going through the horror. Worry about uncertainty. Anxious about the future. Living on the edge. Telling jokes. Speaking knowledgably and taking control. Back to square	Unable to work Reduction in income. Change in life style. Changing roles within the family. Alteration in working patterns. Becoming an outpatient. Hospital appointments. Hospitalisation Changes in interpersonal relationships at work and home.	Feeling guilty receiving income support. Feeling frustrated unable to do things/having to rely on others. Different perspective on life. Feeling isolated. Feeling depressed. Feeling scared. Side effects confusion/despair /hallucinations.	Recurrent infections. Feeling tired. Disabled. Fractured bones. Anaemia. Painful back. Side effects. Altered image. Bone pain. Unable to walk unaided. Breathlessness. Numb fingers. Numb feet.

	one. Ups and downs.			

Table 25 Empirical referents of *Contention*

5.3.7 Defining the concept

A definition of *Contention* developed from this concept analysis within the context of living with a chronic illness, a critical event or life crisis means struggle, battle, disruption and disharmony. It is a multidimensional concept encompassing sociological, psychological and physiological manifestations. These four concepts are closely related but do not necessary happen simultaneously or in any specific order. However, they are all present at some stage as a result of the concept *Contention* appearing. In this instance, the context is living with an incurable cancer that originates in bone marrow called multiple myeloma. For example, there is 'feeling uneasy' (disharmony) at the pre-diagnosis stage. Disharmony comes and goes and is therefore referred to as alternating. It returns when changes occur and the disease is slowly progressing (relapse). By the time a person reaches the Haematologist in the Oncology Department many patients begin to realize that the illness is serious although they are waiting for the results of investigations to confirm the diagnosis and for the consultant to explain what the diagnosis means. Following this there is struggle (difficulty) in coming to terms with the diagnosis, the treatment, complex terminology, hospital environment, and feeling generally overwhelmed with vast amounts of information. Battle commences when the individual is able to see things in a more positive light and starts fighting the disease by taking medication, making necessary adjustments, learning, gaining knowledge and making informed decisions. There is major disruption (upheaval) to life style due to the presence of disease, which has sociological, psychological, and physiological implications. The previously mentioned 'breadwinner' who is no longer able to work and support his wife and family

results in a form of '*employment contention*' causing massive upheaval and emotional conflict.

5.3.8 Concluding remarks

Contention is a unique concept that has emerged as a core category from the data analysis of this grounded theory research project. The defining attributes of *Contention* are frequently seen in the cancer literature but are not clearly defined and are sometimes used interchangeably. Disruption as a search term appears in the literature more frequently than struggle, battle, and disharmony. Disharmony is often apparent although it is hidden within the text and usually inferred through expression. Its presence although assumed is powerful and instantly recognizable. *Contention* appears when struggle, battle, disruption and disharmony are all present.

This concept analysis is based on Walker and Avant's strategies for theory construction. The definition of the concept *Contention* has been developed within the framework of specified critical attributes, constructing cases, identifying antecedents, consequences, and defining empirical referents which emerged from qualitative research data. The implications for nursing practice are universal clarification of commonly used terms, which have been refined and developed through the process of rigorous analysis and a sound theoretical base. The results of this concept analysis provide an understanding of the defined attributes of the concept *Contention* and have potential applicability to other areas of nursing practice such as chronic illness and trauma or accident and emergency nursing. An operational definition of the concept involves identification, exploration and measurement of phenomena. Measurement requires searching for a tool that accurately reflects the defining attributes of *Contention*.

5.4 Contention in communication

Contention in communication implies struggle or difficulty in understanding what is being said or explained. Equally the person speaking may 'struggle' to convey meaning because they are unable to explain clearly what a problem is. For example, a person that attends the GP surgery who has been unwell but is

unable to articulate what the symptoms are because the symptoms are vague yet there is a belief that something is wrong. Thorne et al's (2004) research highlights the experiences of people living with multiple sclerosis and issues relating to communication between patients and healthcare professionals. For example, participants frequenting the doctor's surgery reporting ongoing symptoms which were trivialized in some instances or it was suggested to individuals that their symptoms were of a psychosomatic origin. These encounters often resulted in fear, anger, frustration, loss of confidence and sometimes emotional conflict between spouses (Thorne et al 2004).

Following numerous or repeated visits to the GP (Leydon et al 2003) circumstances may evolve over a period of time which changes normal behavioural patterns. An individual may become frustrated or angry and demanding (assertive) for example because the situation has become intolerable thus the 'struggle' transforms into 'fight' (battle). *Contention* has to be understood in terms of the whole experience, which encompasses emotional turmoil and frustration (disruption to normal well being or existence) and feeling 'ill at ease', confused, frightened or nervous (disharmony).

5.4.1 Delay

Repeated visits to or from the GP and delay in diagnosis in multiple myeloma in this research had extremely serious consequences for some of the participants. This was evident in several narratives: The crucial point here is that participants in this research had fractured vertebral bones at the time of diagnosis. Their condition had become severely disabling and excruciatingly painful as a result of delay in diagnosis. The decision to interview the GPs was theoretically sampled based upon data collected and previously analysed concerning the issue of delayed diagnosis and repeated visits to GPs. The GPs interviewed, however, did not normally see many patients with multiple myeloma despite the location being a main referral area. For example:

Ian (HCP 026) *"on my list of approximately 2,300, 2,200, something like that, actually assigned to me with my name on their notes; we've actually got two. One with multiple myeloma and one with some other weird and wonderful paraproteinaemia".*

The GPs acknowledged that it was difficult to diagnose a rare disease such as multiple myeloma and appeared to struggle when patients presented with vague or unremarkable symptoms. Disharmony appeared in the form of feeling 'uncomfortable' or frustrated because of inadequate equipment in the surgery or learning that patients they (GPs) had seen and examined on more than one occasion, were at a later date diagnosed with a malignancy. One GP stated, for example, that he "*didn't have a crystal ball*" (John HCP 021).

GPs tend to focus on the more common conditions and treat the symptoms rather than attempt to investigate all potential causes (Klineberg et al 2007, Watts, 2005). A common presentation at the onset of multiple myeloma is backache. There were a significant number of patients (n=9) who presented with back pain at the time of diagnosis in this research representing more than half of the patients' participant group. By concentrating on the common potential causes of back pain (albeit an assumption in the absence of an investigation) the uncommon or rare diseases like multiple myeloma are not being considered. Depending on the severity assumptions made were generally of a muscular strain or a prolapsed disc. It appears that individuals accept what GPs initially diagnose without question and if symptoms are subsiding with medication prescribed, their patients are usually satisfied. Backache is a common ailment and according to the GPs interviewed, they saw approximately 3 or 4 patients a day:

John (HCP 021) *"A ridiculous number of all ages, I would say, everyday somebody is coming in with a back problem of one sort or another; and at any given time there are probably 2 or 3 people that you'll be seeing regularly who've got ongoing back problems".*

R: *So as backache's quite a sort of characteristic onset of myeloma how many people do you actually see with backache coming into your practice, say on a day-to-day basis?*

Ian (HCP 026) *"Must be three a day, potentially more".*

According to one GP from South-West London the key is to concentrate on several diagnoses including the more rare diseases surmising that there may be 10 or more possible causes for back pain (Watts 2005). Klineberg et al (2007) discuss 15 potential causes of back pain categorizing them into three groups

namely 'emergent' for example ectopic pregnancy, 'urgent' such as a duodenal ulcer and 'potentially serious' as in pelvic inflammatory disease. Although the majority of cases are associated with minor trauma or degenerative changes in muscles or vertebral discs, it is important to recognise all potential causes to avoid delayed diagnosis which could, in some instances be fatal (Klineberg et al (2007).

There appears to be four contributory factors identified from the data causing delay in diagnosing multiple myeloma, which are (a) GP, (b) patient, (c) policy and (d) the nature of the onset. Similar findings are found in the literature. Mitchell et al (2008) for example maintain there are three possible factors influencing delay in diagnosing colorectal cancer. These are: patient, healthcare professional and hospital delay. Patients for instance apparently either failed to recognise the serious implications of initial symptoms or denied having them. It was suggested that delay associated with healthcare professionals resulted through misdiagnosing and inappropriate investigations (Mitchell et al 2008).

The key contributory factor in this research appeared to be the approach taken by the patients' GPs. For example participants stated that they were not physically examined; prescribed analgesics were ineffective and they didn't feel that they were being taken seriously. The notion of being 'fobbed off' or not taken seriously does not appear to be uncommon (Berg and Ahmann 2006, Picardie 1998). Feelings of anger are naturally directed towards doctors especially when it is understood that appropriate investigations were not undertaken at an earlier stage of the disease (Houldin and Lewis 2006). In this research there was an emphasis on treating the symptoms and increasing the dose or changing prescribed medication when the pain persisted or worsened. Routinely patients with persistent back pain were referred to physiotherapists, which took several months. Two participants attended alternative therapists such as osteopaths and chiropractors prior to visiting their GP surgeries, which may have contributed towards a delayed diagnosis. The nature of the onset of the disease, which is often vague such as back pain, tiredness or mild anaemia, provides an effective camouflage. The cancer therefore is difficult to detect.

It is only when the presentation is considered uncommon, abnormal, severe, or there is a family history of cancer that it is investigated immediately. The policy regarding backache is to treat the symptoms and not investigate the cause until much further down the line when the disease has been allowed to progress. This appears to be one of the major factors influencing delay in diagnosis. A delay in diagnosis ultimately means a delay in treatment. The lingering question is: What difference does this delay make to the patient who has an incurable disease like multiple myeloma? As illustrated in the participants' extracts above delay in diagnosis allowed the disease to progress and bones to fracture which required surgical intervention. Emotionally this had a monumental impact on participants, as they were frustrated and angry because it was felt that the diagnosis should have been made earlier. This anger was directed at their GPs. As a result of the delay the physiological impact had escalated to intense and disabling conditions. The implications of delay in detecting myeloma for patients with advanced bone disease synonymous with poor quality of life may mean exclusion from the more aggressive treatments such as high dose melphalan reducing chances of survival even further.

In contrast to the delay there were instances when participants were diagnosed relatively quickly. The following exemplar is an illustration of how an investigation was instigated as a direct result of the way in which the individual communicated with the GP during the first visit. Using powers of persuasion and asserting herself Stella (F 013) challenged the GP and demanded some action (Table 3). This 'challenge' was based on personal knowledge and her close relationship with her daughter Debs. Stella was able to distinguish between her daughter being ill (vomiting) and being pregnant (vomiting). The GP was not able to make such a distinction.

In this case (Debs) the disease was suspected following routine blood tests, which showed high blood calcium levels (hypercalaemia). Hypercalcaemia is a condition that results from bone destruction and is associated with myeloma (Foerster 1993). Elevated calcium levels are also associated with hyperparathyroidism which was discussed as a potential diagnosis with the participants (Stella and her daughter Debs). Diagnosis of myeloma is confirmed

by specialised blood, urine and bone marrow tests (aspirate and trephine biopsy). The blood and urine tests (electrophoresis and immunofixation) will detect and type a monoclonal protein spike present (Smith et al 2005). Routine blood evaluations would not therefore be useful in the absence of hypercalcaemia. Professional opinion may sometimes be swayed by pressure put on GPs by either the patient or a family member. The difficulty is understanding that specific investigations are required for a particular condition or 'suspected diagnosis'. When confronted with demanding patients the GP may arrange a referral or an investigation such as a blood test at the request of the patient simply to provide some reassurance:

John (HCP 021) *"I think it's perfectly legitimate to refer people for reassurance to whoever, whether it's a neurologist, you know this person is worried that they have got cancer, this person's worried that they've got, you know, a significant back problem. I've examined her, I don't think there is anything but I can't really, you know I can't allay their fears".*

5.4.2 Bad news

Communicating bad or significant news was a primary cause of *Contention*. A diagnosis of multiple myeloma meant informing participants that their disease was not only malignant but also incurable. The news appeared to have a monumental impact on the recipients causing disruption to life in the form of major upheaval; disharmony in terms of feeling confused, unsettled and shocked; struggle meaning difficulty in understanding what was happening to them and battle or fight which appeared typically in terms of asking questions, learning about the nature of the illness, how it will effect their lives and how the illness is managed or treated.

The ways in which this situation was approached varied considerably depending on the individual consultant or haematologist involved. Two consultants with different approaches implied that patients would have entirely different experiences depending upon which clinic they attended or which room they sat in. For example one consultant 'painted a bright picture', which could be construed as too 'glossy', and another consultant simply informed the patient that it was unlikely that they would survive for more than five years (Table 4). Here we have two extremes neither of which seemed a satisfactory approach.

Back and Arnold (2006:4209) compare a "cheerleader mode" which aims to deliver hope with a "blunt and sometimes brutal" but more realistic approach when discussing a bad prognosis. These authors (Back and Arnold) argue that the most common strategies employed by doctors when dealing with communicating bad news are realism, optimism or avoidance.

Berg and Ahmann (2006) reported on significant differences between a surgeon and an oncologist regarding their individual approaches to the disclosure of bad news to the parents of an infant with a malignant brain tumour (pineoblastoma). The surgeon for example informed the parents that an operation was required to relieve symptoms of pressure caused by the tumour and to perform a biopsy. The conversation took place in a busy and open area by the nurses' desk. A detailed, factual rationale for the procedure and potential outcomes was explained without showing any signs of warmth or compassion. The oncologist, on the other hand, who confirmed the diagnosis, dealt with the situation in a quiet room with a more humane and compassionate manner taking on board the distraught parents' emotional needs.

The following account differentiates between a consultant who communicated 'consistently well' while others appeared to have 'an agenda' and a restricted amount of time in which to deal with the situation. Thus there is a desire to act swiftly concentrating on information that they feel legally and ethically obliged to divulge regardless of the emotional impact this may have on the patient and family:

Fiona (HCP 039) "*You do see a big difference in how different people deliver bad news, or difficult news, difficult information. We've one consultant who has a keen interest in good communication skills and so he consistently does it well. He takes time; he gives very relevant information but doesn't give too much in the sense that he's not overwhelming. He allows time for information to sink in and asks the patient or the family if they want to ask anything about what he's just said before moving on to the next bit. But on the other hand I've come across consultants who have an agenda and they feel this is the information I need to give this person, because that, they feel, I've got this amount of time and I need to give this information, without really thinking about how the patient, whether the patient is even ready for that information*".

The reality and consequences of dealing with substantial numbers of patients in haematology outpatient clinics and meeting government targets has had a profound effect on the duration of consultation times. The study centre had recently increased clinic days from two to three days per week to meet the additional demand. The supportive role of the clinical nurse specialist appears to be compromised at the expense of these time constraints 'picking up the pieces' and taking the brunt of the emotional impact at the time of the diagnosis:

Claire (HCP 038) "*You know, clinics are just 15 minutes, appointments aren't long, they're very busy and frenetic and people are kept waiting, we're no different from any other hospital*".

Karen (HCP 022): *"Although the doctor would tend to go through their diagnosis, they tend to do it probably in 15 minutes and I would then probably spend an hour going through the diagnosis in more detail and answering their questions and picking up any pieces and" ...*

5.4.3 Emotional labour

Communicating bad news is exceedingly arduous (Vandekieft 2001) and working as an oncologist is deemed "inherently difficult, and racked by emotional and psychological traumas" (Lyckholm 2001:750). The emotional impact of disclosing bad, sad or significant news on healthcare professionals is monumental yet it has received little attention in the literature (Arber and Gallagher 2003). It is particularly stressful for many oncologists who find it difficult dealing with patients' emotional reactions (Dias et al 2003). Situations vary according to level of expertise, patient's age and whether a relationship is well established between patient and doctor (Dias et al 2003). It is surmised that in relation to multiple myeloma *Contention* arises when healthcare professionals struggle with difficult situations and intense emotional responses from patients and their families. Events associated with bad or significant news, for example periods of unstable disease are synonymous with the trajectory of the illness:

Claire (HCP 038) *It's not just an academic brain, it's seeing the individuals and seeing them as, as individuals and just appreciating how awful this is for them...and Ed* (consultant haematologist) *does that very well and you can clearly see that he's devastated and that he struggles, as a lot of haematologists do, I think*".

Emotional labour in nursing both in non-specialised and highly specialised clinical areas (Mohan et al 2005, Kelly et al 2000) is a salient reminder that healthcare professionals may struggle because events they are continually dealing with are 'emotionally draining' and often difficult to manage. The myeloma clinical nurse specialists interviewed in this research suggested that the emotional impact on them was, at times, far greater when seeing newly diagnosed patients as this was determined by how positive or negative the approach taken by the consultant haematologist was deemed. In other words the responsibility of managing 'emotional backlash' from patients and family members (when the diagnosis was confirmed) was transferred from the consultant haematologist to the clinical nurse specialist. This became burdensome depending on how the situation was initially managed:

Karen (HCP 022) *"I struggle with it because I'm much more on the sort of positive side"*

Fiona (HCP 039) *"It makes me feel uncomfortable and again when I'm in there in that situation, I'll often say to patients that this is something we can talk about again"*

5.4.4 Complex language

Complex terminology in haematological oncology, communicating with healthcare professionals, communicating with children and hidden disclosure were significant issues that emerged from the data. Healthcare professionals specialising in this field of practice were so familiar with haematological language that it became ordinary. Thus it appeared to 'desensitise' healthcare professionals when communicating with patients and their families (Berg and Ahmann 2006) indicating that communication was at times ineffective because of the medical terminology used. From a healthcare professional's perspective entering the area of practice for the first time, the language was perceived as highly technical, foreign and challenging. McGrath et al (2007) corroborate this statement and provide evidence of parents of children with acute lymphoblastic leukaemia, also from a healthcare professional background, who appeared to have difficulties understanding complex and unfamiliar terminology causing significant barriers in communication. An appropriate period of time therefore was required to study the terminology and become accustomed to it. From a

layperson's viewpoint it is argued that the use of terms such as plasma cells, stem cell transplants, myeloma and paraproteins increases anxiety and adds to the bewilderment and trauma associated with the diagnosis. This implies struggle, battle, disruption and disharmony (*Contention*). Evidence from this research suggests that patients were sometimes given information that they did not understand because of the complexity of medical jargon. Furthermore it was suggested that the disclosure of the information was sometimes rushed (Berg and Ahmann 2006, Ptacek and Ptacek 2001, Thomas and Retsas 1999) and overwhelming due to the volume of information devolved. For example confirmation of the diagnosis was often followed with a detailed discussion on various treatment options. This could however be viewed as a swift move towards focusing on the positive aspects, reassuring patients and their families that although the cancer was incurable, treatment was available to manage the disease and prolong survival.

5.4.5 Talking to children

'Communicating with children' as an emerging issue was a reflection on the increased number of younger patients diagnosed with myeloma, which was mainly perceived by healthcare professionals who participated in this research as a disease of the elderly (Kyle 2002). A significant number of patients had children under the age of 12 years (n=6) and seven couples had children in their late teens. Talking to young children was problematic because the parents were uncertain of what to say and how to say it. Participants in Houldin and Lewis's (2006) qualitative study about newly diagnosed patients with advanced colorectal cancer struggled with how and when to talk to the children about the cancer, concerned that the disclosure may interfere with their progress at school or socialising with their friends. Alternatively talking to children and explaining about the illness was not perceived as a problem because the child was considered too young to understand. The consequences of underestimating a young child's perception and ability to understand can have a detrimental impact on the child's development and well being (Scott et al 2003). In this research for example it was explained to Debs (P 009) and Mat's (F 010) son Ben aged 3 that his 'mummy' was going into hospital to 'get better' and Ben understood that his mother would be able to walk when she returned home from

hospital but this was not the outcome he had anticipated which caused him to become upset (Table 6). The concept of *Contention* in communication and the way in which that communication is interpreted by a young child for example, may provide a useful framework to enhance explanatory power and understanding of interactions between parents and their children. .

5.4.6 Hidden disclosure

Hidden disclosure and managing the reality of the situation emerged from the research data. The disclosure was either 'total' or 'partial and gradual' undertaken to protect loved ones from knowledge that was considered psychologically injurious. Individuals develop coping mechanisms such as 'denial' or/'acceptance' (Copp and Field 2002) and some avoid any discussion with close family members concerning illness or dying in order to protect one another (Smith and Cox 2007). Some people are unable to express their feelings without getting distressed and consequently others within the family feel isolated (Houldin 2007, Simpson 2005). Some of the participants in this research appeared to be unable to disclose their true feelings and talk openly with their partners or other family members who were perceived as unable to cope. Some participants believed they were a burden to their family (McPherson et al 2007, Thome et al 2003) resulting in emotional conflict, feelings of abandonment and disharmony. Hidden disclosure also involved deliberate attempts to take on board selective information that was viewed as positive, while 'blocking out' or not wanting to take on board any negative feedback with the aim of sustaining hope:

Alf (F 004) *"It's not a very nice illness...you can ask the question how's Pam and you might say well that's OK, that's OK but that's not very good and that's not very good. Well you don't want to hear the not very good part"..*

5.4.7 Sustaining realistic hope

Sustaining realistic hope when someone has an incurable and progressive illness is problematic (Clayton et al 2007) and was mainly achieved by the research participants in relation to short-term goals such as a trip away or attending a family wedding. It cannot be predicted how long patients will

survive following a diagnosis of multiple myeloma. The medium survival remains 3-4 years (Bradwell 2006). Some people may only survive for a year following diagnosis but there are those who live for ten years or more. One participant discussed the meaning of 'battle' or 'fight' in relation to sustaining life: "*It's an ongoing fight. I mean...you know, the fight is to sustain life; it's as simple as that, that is the fight*" (Frank P 007).

It is rare for a patient to survive for twenty years. For example, there was only one patient at the study centre who had survived for twenty years. *Contention* arises through the uncertainty of the unknown length of time for survival which is discussed in the next section. Healthcare professionals realise how important it is to remain positive (Dias et al 2003) however it can induce false hope and it is misleading to imply that patients can live for the potentially maximum period of time:

Karen (HCP 022) *"When I talk to patients I try and stress that you know, we don't know but the average survivor lives three to five years but within that, you will get some people who will only survive for a year but then we also have patients who are 20 years post their diagnosis and that at this stage we can't predict".*

5.5 Contention in nature of disease

Continuing from the previous statement the unpredictability of myeloma is a major cause of *Contention* because of disruption and uncertainty in the lives of people living with the disease. Numerous expressions were found in the research data such as 'living on the edge', 'living with the sword of Damocles over you', 'having an albatross around your neck', 'it is a ticking thing', 'a time bomb', 'living on death row', 'a death sentence', 'living with all the uncertainty', 'a rough old ride', 'the ups and downs' and 'roller coaster'. Many of these expressions reflect the struggle and disharmony constantly present. Similar expressions are commonplace in the cancer literature. The nature of myeloma and living with uncertainty are synonymous. The concept of uncertainty is associated with other diseases (Shaha et al 2008, Haugh 2005, Winterling et al 2004, Winters 1999 and Dudley 1995), In the context of living with a rare and progressive cancer such as myeloma, uncertainty is viewed as intensified, prolonged and entwined in a linear relationship to the pathway of the disease,

which, in itself, is unpredictable with an unforeseeable future. The differences between this disease (myeloma) and other cancers are the presence of bone disease and the unrelenting and ongoing periods of relapse. Individuals are living with an incurable cancer and despite all the novel chemotherapy agents, clinical trials and stem cell transplantations, the impact or effectiveness of the treatment may only last for days, weeks or months. This does not appear to occur with other cancers.

In a recent review of the cancer literature (Shaha et al 2008) causes of uncertainty in common cancers such as breast, prostate and colorectal were identified as: inadequate information, decision making in relation to treatment options, coping with the cancer and impact on daily living. The 'ups and downs' or 'roller coaster ride' terms (Carter et al 2004, Nason 2004) in this research specifically relate to the repetition of myeloma relapse. Uncertainty is also associated with response to treatment and whether or not the therapy will effectively stabilise the disease. It is not unusual for chemotherapy to be exchanged following 2-3 cycles due to an escalation in progression of disease or severe toxicities (adverse events) that may result from the medication administered. Nason (2004) reported on two failed lines of treatment while in the meantime the disease progressed unrelentlessly. Although individuals adapt and cope with their illness, they tend to cope much better knowing that treatment is still an available option (Clayton et al 2007).

5.5.1 Becoming knowledgeable

The majority of patients and family members in this research became knowledgeable and familiar with the complex terminology which is associated with the cancer and the management of the disease (procedures and treatments). Gaining knowledge meant having control (Houldin 2007) and being able to judge progress (Thome et al 2003) and being able to cope at home as a patient or a caregiver (Mok et al 2003). Although in some cases there appeared to be interest and enthusiasm to learn, others may have struggled to do so. Learning the 'new language' was both challenging (battle) and daunting (struggle) and may have been viewed as a necessity to communicate effectively with the healthcare professionals. This may also be a reflection on the period of

survival, which ranged from 20 months to 20 years allowing time to develop from 'novice' to 'expert patients'. Examples of' 'expert' patients were previously shown in Table 11. With the exception of three participants diagnosed between 2006 and 2007, two of the patient group could be categorised as experienced patients who chose not to become involved with familiarisation of terminology or learning about the disease. These participants appeared 'detached' and attempted to 'block out' any knowledge associated with the illness as a way of coping. Participants aware of the impact of bone disease and potential consequences lived with uncertainty regarding their future physical capabilities, which had a substantial psychological impact and threatened their quality of existence in numerous ways creating disruption and disharmony. This is abundantly clear in the following two excerpts:

Debs (P 009) "*They've been very good at work, I'm still, I'm being paid sick pay but I don't know how long that's going to go on for, you know, with the anticipating of sort of going back but I'm not sure if that's ever going to happen".*

Geoff (P 011) *"It's just not knowing what course the disease will take next year. You don't know how it's going to affect you. There are people I've spoken to who've had severe back problems. I said to, either Tom or Harry* (consultant and registrar) *should I pack up playing golf, is swinging a golf club, I know it's how it broke, my arm, broke it in the first place, but will I one day, just have my spine go while I'm playing"?*

5.5.2 How others perceive us

Struggle emerged in relation to perceptions and how others (family and friends) viewed the illness particularly when there were no visible signs and the patient looked or appeared healthy. Rupert (1987:21) discussed her myeloma in terms of an "assault from within" and objected to others complimenting her on how well she looked as this was interpreted as:

"Because I looked well I must ***be*** *well"* page 22.

Adverse events or side effects from medication were sometimes so severe that these manifested as the only obvious visible symptoms and changed other peoples' perceptions of the illness. Visible symptoms signified legitimate disease convincing family members that it existed. Newly diagnosed cancer

patients with leukaemia and malignant lymphoma experienced difficulties convincing others of their illness because they appeared to look well (Persson and Hallberg 2004).

Multiple myeloma is not generally associated with young people or parents of pre and school aged children, which was found to be significant in this research and a reflection of the decreased median age at diagnosis (Schey and Pallister 2004) The argument here is understanding that this younger population of patients have different issues to that of the elderly population of patients. Younger caregivers' experiences of newly diagnosed advanced colorectal cancer with children reported higher levels of distress (Houldin 2007). There appears to be far greater disruption and disharmony impacting on family life when the father of a young family becomes incapacitated and can no longer rely on an income to support them. This kind of 'supportive care' needs to be recognised by healthcare professionals. Equally pertinent is for patients and families to understand that healthcare professionals are in a position to assist or refer them to the appropriate person who can advise and support them. The discussion continues with *Contention* in impact on life.

5.6 Contention in impact on life

Contention associated with life for the participants and that has been reflected in the literature, meant total disruption (Houldin 2007, Houldin and Lewis 2006) and chaos (Persson and Hallberg 2004) to normality and life, as it was known prior to the onset of the illness. It was described in terms of normal existence and daily living hitting a 'dead stop' or "standing still" (Houldin and Lewis 2006:722) and dramatically changing. Future plans were either postponed or destroyed. In relation to this research, the presence of bone disease can be exceedingly debilitating because of constant pain and the fragility of skeletal bones predisposes to multiple fractures. Some of the participants were not able to return to work because of disability. Others who managed to continue had non-manual jobs (information technology, finance and banking) despite disruption to normal working patterns caused by ongoing hospital appointments and treatment regimes resulting in significant periods of absenteeism. Commuting or travelling was viewed in terms of struggle. Participants aimed to

avoid crowded public transport to isolate themselves from potential infection due to their immunodeficiency. This was a constant source of worry following chemotherapy on the day care unit and travelling home during the 'rush hour'. The anxiety associated with delay or being detained longer than anticipated is viewed in terms of struggle and 'feeling on edge' (disharmony). All cytotoxic medications cause bone marrow suppression with the exception of vincristine and bleomycin (BNF 2006). Thus the immunodeficiency associated with the myeloma is further exacerbated by the chemotherapy. Participants were usually acutely aware of the potential consequences and therefore felt vulnerable following treatment.

5.6.1 Impact of treatment

The physical and emotional impact of treatment was another major source of *Contention.* In this research, as in other research, people not only struggled and fought (battled) the disease; they struggled and fought (battled) the physical and psychological consequences of treatment they had to endure (Houldin and Lewis 2006, Persson and Hallberg 2004, Thome et al 2003). For example the physical and emotional trauma dealing with invasive and ongoing cycles of intravenous chemotherapy over prolonged periods involving repeated punctures from needles (cannulations) resulting in arms full of bruises, abrasions, associated anticipatory trepidation and feeling 'ill at ease' (disharmony) in the interim period prior to the administration. The dilemma of toxicity of the medication has to be weighted against its efficacy and the individual's safety and well-being. Patients are sometimes reluctant to report adverse events because of the fear that dose of medication will be modified (dose reduction) and it is then viewed as less effective; or treatment may be discontinued and there is the fear that the disease will progress or worsen.

The physical impact of treatment ranged from mild to severe and in some instances life threatening, for example deep vein thrombosis and substantial internal haemorrhage. The haemorrhage, in this instance, may have been precipitated by two factors: the use of non-steroidal anti-inflammatory drugs for bone pain and the destruction of stomach membranes caused by the

chemotherapy. (Sylvia's husband Bill had taken Brufen (Ibuprofen) occasionally for his bone pain):

Sylvia (F 028) *"He* (surgeon) *said it was all the chemotherapy that had burnt all the lining of the stomach away and because of all the neutropenia and all of that...as soon as they was putting it in* (blood), *it was just coming out...because there was nothing there, you know platelets to clot the blood, and he was the one who turned round and said to me make sure your husband never ever takes any anti-inflammatory drugs"...*

Ray Grummett's reference to his stomach lining (Grimmett 2006:87) was related to his inability to eat:

"There are white spots in my stomach and it seems that the stomach lining has not grown back after the ravages of the chemo. When I was in Addenbrooke's (hospital) *the skin on my fingers split and eventually fell off, and was quite unpleasant. The doctors also said that the same thing would be happening to my gullet and gut, so it is hardly surprising that my insides are a shambles".*

Four participants complained of permanent damage to peripheral nerves affecting their hands and feet induced from medication, which had a profound and disruptive impact on the quality of their lives. The effects from steroids used to treat myeloma such as dexamethasone were particularly troublesome causing patterns of unusual behaviour, which was out of character. One participant described himself as an "irritable monster" (Dave P 023), which he attributed to his dexamethasone. Another (Fred P 017) complained that he had become short-tempered 'snapping' at people resulting in emotional conflict **and** disharmony (Table 14). McGrath et al (2007) report on disturbing psychological adverse events such as aggression, isolation, confusion and depression associated with the treatment of dexamethasone in children with acute lymphoblastic leukaemia. This had a substantial impact on family members who were described as "exhausted from the prolonged treatment process" (p 90).

The emotional experience associated with high dose therapy (stem cell transplantation) described as one of the most unpleasant hospital experiences was due to physical and psychological consequences of this particularly aggressive treatment. Carlson and MacRae (2002) include elevated levels of stress, anxiety and depression prior to and following the transplant procedure. A major theme in the meaning of experience associated with leukaemia and stem

cell transplant was the aim of achieving a cure (Haberman 1995) as opposed to achieving stability of a progressive and incurable myeloma. This was an experience that participants in this research endured more than once knowing that it could potentially extend their survival.

5.6.2 Impact on sexual relationships

Contention caused as a result of impact on sexual relationships and family life emerged in terms of disruption, chaos, upheaval and emotional conflict (disharmony). Sexual relationships were disrupted or damaged as a result of the disease and the effects from treatment (Thome et al 2004, McGrath 2001, Rice 2000). Although sexual support may also be enhanced within a relationship during illness (Houldin 2007) sexual activity became intolerable for individuals who were debilitated because of pain associated with bone lesions or fractures particularly involving the spine, chest, hips, pelvis and upper thighs. Sexual disruption was also caused through fatigue, erectile dysfunction and the development of one penile tumour creating a private and hidden struggle for the individuals concerned. One participant was tormented and agonized over the impact this had on his wife despite the fact that as a couple they were able to talk about the problem. It remained a concern:

Mike (P 040) *"I cannot really, you know, well make love to my wife, satisfy her the way that I should but you know, that is a worry for me in a sense but again, worried about it yes, but worry cannot fix it. You know cannot make it better. I think about it sometimes but yes try to put it at the back of your mind really because that's not going to help".*

5.6.3 Impact on family

Changed domestic roles within the family home environment (Simpson 2005) took place where, for instance the male partner exchanged roles with the female who was ill or incapacitated, taking on board the household duties traditionally done by the female such as shopping, laundry and cooking. Alternatively the female took on responsibilities traditionally done by the male such as attending to the household bills or orchestrating assistance from other male members of the family for 'heavy' work such as furniture moving, gardening or repairs. Family life appeared to alter significantly more for those with children living at home. Examples included the problem of storing vast

quantities of medication in the home away from the children; adult children preparing meals for parents; adult children escorting a parent out in a wheel chair; and having to rely on other family members or friends to take care of infants. In contrast children in their late teens or early twenties away at university or living away from home were perceived as 'getting on with their lives' and doing what they would normally be doing:

Carol (F 012) *"The kids by virtue of the fact that they do live, you know they're doing everything that they normally did. I mean since Geoff's been diagnosed, Nancy's been around the world for a year. You know they both finished their degrees. Fran's been off travelling to Australia and New Zealand, you know Nigel's doing all the things he'd do, which means that they've kind of got an inbuilt faith that everything is going to be OK. Do you know what I mean? Which is quite reassuring really, you know the fact that it hasn't, we the family life hasn't changed. The kids' lives haven't".*

Struggling between the illness and being a parent proved to be a major source of *contention*. Loss of identity as a parent and loss of parental control were viewed in terms of frustration, disappointment and anguish. The desire to regain parental identity and control became overwhelming. Examples included termination of pregnancy, taking care of the child (Table 17), walking with the child and carrying the child which the parents were no longer physically able to do:

Debs (P 009) *"He* (Son Ben) *is looking forward to when I can go out for a walk with him".*

The monumental impact on the family and psychological distress appeared more intensified because of significant life events and the time of life (Houldin 2007) that the disease struck particularly in relation to the participants with young children. Their lives were in a constant state of turmoil and domestic upheaval because of the debilitating effects of the disease. Jack (P 014) for example was no longer able to take care of his toddler Nathan in the evenings while his wife went to work. Hiring a reliable child minder was a constant worry. This couple had no extended family members living in the UK and felt that they could not continually accept offers of help from friends:

Jack (P 014) *"We can only ask so much of friends, before you feel uncomfortable about it and friends offer all the time and we can say thank you*

very much of course but you don't want to take them up on it all the time".

In contrast to the lack of family support, taking on shared responsibility of younger children when a parent was incapacitated meant that the lives of those individual family members involved were also 'on hold' or at a standstill having a disruptive impact. For example, other research findings suggest individuals rearranged their working lives (Wideheim et al 2002), cancelled social engagements, took unpaid leave and made themselves available. Simpson's (2005) portrayal of Chinese women with breast cancer reported that their partners or family members were constantly with them providing the physical and emotional support they needed.

Hospital appointments and prolonged treatment regimes including the aftermath appeared to dominate the lives of participants and their families. Travel between local and specialist hospitals and parking the car was problematic in terms of finding somewhere to park (a constant battle) and additional expenditure.

Ways in which families coped during difficult periods such as when the disease had progressed significantly or was no longer responding to treatment ranged from a "conspiracy of silence" (Brennan 2004:100) in order to sustain hope and protect each other (Simpson 2005) to talking openly and making realistic plans. Maintaining a 'conspiracy of silence' may be viewed as a struggle (hindrance) or a battle (challenge) when communicating with each other as members of the family must be 'on their guard' the whole time or establish ways of creating a positive atmosphere. Either way may cause an additional burden, disruption and disharmony in normal family communication. Identifying emotional support needs such as family counselling would therefore potentially be helpful in facilitating openness in communicating within the family who are unable to talk or come to terms with a loved one's deteriorating condition and impending death. *Contention* in supportive care needs follows.

5.7 Contention in supportive care needs

Similar patterns emerged throughout the data relating to problems or barriers accessing supportive care services. *Contention* was identified through struggle,

conflict and fight (battle) experienced by participants as a result of their supportive care needs not being adequately met or acknowledged. It is suggested that lack of recognition of specific supportive care needs was linked to rarity of the cancer, lack of awareness and lack of knowledge. Having a rare disease means coping with the illness and with other peoples' ignorance (Joachim and Acorn 2003), which represents a challenge for the individual family concerned, and for members of the public. Therefore individuals in a position to facilitate access to supportive care services were, in some instances, oblivious to the impact and consequences of the disease. For example, outside the haematological oncological arena participants were dealing independently with external agencies such as employers, DHSS and insurance companies. Even within other areas of healthcare it cannot be assumed that healthcare professionals are familiar with the term multiple myeloma. In a GP's surgery, for instance, practice nurses admitted they had not heard of the cancer:

Pam (P 003) *"At times I'd go to... even like a nurse at the surgery or ...if I had to have blood tests or anything and I used to say, I have myeloma, they used to go myeloma? What's that"?*

Invisible struggle, impact of policy and decision-making were key issues associated with supportive care needs.

5.7.1 Invisible struggle

Invisible struggle emerged as problems or difficulties in participants' daily lives associated with the illness but not immediately apparent or observable. Various reasons may prevent individuals discussing problems they have other than medical matters. They may be too embarrassed if issues are of a sexual or financial nature (McGrath 2001). It could be that the role of the healthcare professional is perceived as 'departmentalised' and can only deal with the cancer and its treatment. The outpatient setting may not be a conducive environment for such disclosure. Patients and family members may not wish to discuss what might be considered as 'private family business' with healthcare professionals. Furthermore patients may not be asked a specific question which would provide the opportunity to respond and allow discussion concerning a particular problem they may be experiencing at home or at work. Examples of

invisible struggle included difficulties with completing mammoth and complicated DHSS application forms and experiencing difficulties accessing support such as incapacity benefit. In one case the struggle, conflict and battle continued for seven years during which an annual independent medical assessment was undertaken to assess whether the participant was fit enough to resume work:

> Bill (P 027) *"They* (DHSS) *used to send their doctor round to assess me. They wouldn't take notice of my GP or the hospital, no; they always had to have an independent chap come round. But I think it was about four years ago, that I finally got a letter from them saying that...we now recognise that your illness is indefinite and ongoing".*

Financial struggle was a major concern and participants worried about the colossal amounts of money spent on travelling to the hospital, petrol and parking the car. One participant's invisible struggle was not knowing or understanding the healthcare and social system in the UK as he had only lived in the country since 2003. He was unaware of what help he may be entitled to and had problems convincing colleagues at his place of work that he was ill. The consequences of this meant that he had not yet received statutory sick pay and was struggling financially (Table 19, Victor P 030). Nine out of eighteen Bangladeshi families in East London referred to a community-based palliative care facility were reported as having serious financial problems through borrowing money from relatives (Spruyt 1999).

Another participant was very resourceful and had not only studied the disease but familiarised himself with approaches to accessing supportive care advocated that most individuals did not have the *"forcefulness or the demeanour or whatever to actually deal with all the flack that you get or dealing with disappointment"* (Phil P 019). The evidence suggests people struggled and battled in their efforts to access help and supportive care. Phil was referring to liasing with people at the DHSS and insurance companies. This participant (Phil P 019) was disappointed at the sudden withdrawal of his private health insurance following his stem cell transplant (undertaken by NHS Trust professionals) invalidating the insurance cover. Insurance companies tend to base their decision on whether the condition is defined as chronic, unsuccessful

treatment or the illness is terminal (Pallot 2004). The withdrawal of private healthcare insurance is particularly stressful and disruptive when patients are going abroad and may require urgent medical attention.

5.7.2 Impact of policy

Recommendations produced by NICE are based on the clinical evidence provided and cost effectiveness that is considered appropriate for a modern NHS. The policy taken to withdraw the availability of bortezomib (velcade) caused a great deal of controversy, alarm and anguish. *Contention* emerged through sheer desperation and the difficulty participants had in coming to terms with this decision which caused anger, frustration and disappointment. Psychologically patients felt that their lives were undervalued and potentially shortened. Uncertainty and disharmony constantly present in the lives of those individuals living with multiple myeloma appeared to be further exacerbated as a direct result of the decision concerning the availability of bortezomib.

As stated in the Findings Chapter, following an appeal, a final appraisal report (July NICE 2007) indicated the medication would be available on the NHS for patients following their first relapse having had one prior therapy providing they have had, or were not eligible for bone marrow transplantation. This policy excluded a vast number of the myeloma population namely those who have relapsed more than once restricting their treatment choices. This decision impacted on patients, family members and healthcare professionals. The following healthcare professional suggested that patients would be able cope better emotionally if everything possible had been tried:

Nurse Karen (HCP 022) *"I think patients actually cope better, we've got some patients who you know, they've had velcade, they've relapsed from their velcade and they're saying you know, there isn't any options now, you know I appreciate, I know, we can go back through some of the others but nothing is now going to hold it for very long and I'm looking towards palliative care, and that's OK because they feel that they've done everything but for these patients where there are these other options around and they're just not allowed them, it's just so difficult to think that nobody values your life".*

5.7.3 Decision-making

Contention in decision-making was associated with the struggle individuals faced when confronted with having to make difficult decisions they felt unable to make especially concerning treatment options or significant life events. Difficulty in making decisions regarding treatment options often coincided with the time that the diagnosis was confirmed. Participants were therefore often in a state of shock and bewilderment while at the same time struggling to concentrate on explanations concerning managing and controlling the disease. It is suggested that in some instances participants were encouraged to participate in clinical trials undermining their freedom to choose. Some of the participants felt that they were being rushed and simply 'swept along with the moment', consenting but not understanding everything that was happening to them. Participating in a clinical trial may be the only solution for some individuals who have had several lines of therapy because of immediate access to novel agents that might not be available within the NHS Trust. Struggle in relation to decision-making is often transformed into battle or assertiveness particularly when the patient has experienced more than one line of chemotherapy. The experience and knowledge gained, for example enhances awareness and understanding which enables the individual to make a more informed choice.

However for individuals who are newly diagnosed a clinical trial is an additional option to traditional therapy. Decisions should not be made merely to accommodate clinical trial recruitment targets. Individuals may base their choice of therapy on the method of administration or whether they could be treated nearer their home at the local hospital. Oral medication may appear attractive to patients compared to the more invasive intravenous therapy. Taking tablets at home and avoiding additional trips to the chemotherapy day care unit for the administration of intravenous agents was considered a preferable option for some:

Dave (P 023) *"The actual experience of getting chemotherapy is not, not really fun because you know it's going to make you tired, it's going to make you washed out, or whatever, even though medically it's very necessary. I must confess I much prefer thalidomide because that's taken in pill form".*

The majority of participants were in a position which enabled them to make informed choices once they had passed the 'novice stage' and had gained an adequate level of knowledge and understanding of their illness and how it was managed. The consultant haematologist is generally viewed as the expert and many will be guided in their decision-making. A minority of participants did not actively engage in the process of decision-making and allowed the healthcare professionals to take complete responsibility as was found in Thome et al's (2003) research. The healthcare professional has a moral and ethical duty to provide all the relevant information available so that individuals can make informed decisions. However the timing is crucial and if the individual is in a state of shock or bewilderment it may not only be considered an unproductive exercise but an immoral one. Clayton et al (2007) highlight the importance of asking the individual if they can cope with the additional information at this particular moment in time.

Contention that occurred in decisions that related to significant life events varied considerably from struggling to get to a family wedding or taking a holiday, to moving abroad to be near family and termination of pregnancy which had a devastating impact on the family at the time of diagnosis. The intensive treatment of combined chemotherapy agents and radiotherapy required for the areas of severe bone pain in this case may have resulted in severe birth defects (Weisz et al 2001).

5.8 Applicability of Contention in relation to other chronic illnesses

The basic premise underpinning the theory of *Contention* is the assumption that it is applicable (fittingness) to other chronic and progressive diseases such as Parkinson's or Alzheimer's disease for example. Thus it is suggested that the defining attributes of *Contention* contribute to the understanding and meaning of living with other chronic, progressive and debilitating illnesses.

In contrast to multiple myeloma, Parkinson's and Alzheimer's are relatively well known diseases although Alzheimer's (a form of dementia) is far more common. There are approximately 120,000 people living with Parkinson's disease (Carter 2008) many of whom will also develop dementia (Noble 2007). According to the

Alzheimer's Society, there are about 417,000 people with Alzheimer's disease in the UK (**www.alzheimers.org.uk**). The figures 10-15,000 people living with multiple myeloma appear minuscule in comparison highlighting the rarity of its incidence.

A similarity between Parkinson's disease and multiple myeloma is that they both affect more males than females (Bury 2005). Alzheimer's on the other hand is more prevalent in females than in males (McCabe 2008). These specific diseases will inevitably have different meanings to people, a profound impact on the individual who is afflicted and both Parkinson's and Alzheimer's can have a devastating impact on family members and friends. For example life was totally disrupted for a 17 year old daughter who took on the responsibility of her father's care while her mother was at work (Altschuler 1997). The family found it difficult to discuss the illness (Parkinson's) and while the condition deteriorated and her father's needs increased, the couple's teenaged daughter became anorexic and needed professional help (Altschuler 1997). The nature of disruption in someone living with Alzheimer's disease and the impact on family life can be categorised as catastrophic and relentless. A 73 year old man, for example, continued to care for his wife at home with assistance from professional nurses. His wife had lived with Alzheimer's disease for 10 years and she no longer recognised her husband or their children:

"*This illness didn't just destroy Anna's mind, it has killed something in me, in the family too. If anyone asks about Alzheimer's tell them it is a disease of the whole family*" (Kleinman 1988:183).

Regardless of the nature of the illness each family is unique and family members will react to illness in their own unique way. Influencing factors such as culture, knowledge, education, mass media, personal values and beliefs, individual characteristics, circumstances, social and religious orientation may determine how an individual family cope and respond to illness (Altschuler 1997). It cannot be assumed, however, that family members will always be compassionate or collaborate in order to provide support when it is most needed. Partners may not be able to cope and inevitably relationships can deteriorate and end in separation because of the illness (Fleming et al 2004).

Contention in the nature of Parkinson's disease, for example, is explicated in terms of struggle and fight or battle in relation to the debilitating and progressive course of the illness and its impact (Fleming et al 2004, Habermann 2000). Disruption to life clearly emerges in the literature: "*My world had turned upside down*" (Fleming et al 2004:518). A significant decline in attending social events or receiving invitations is reported and some individuals deliberately stay away from public scrutiny. The disease manifests itself through characteristic and unpredictable periods of sudden loss of physical mobility which is disruptive and frustrating. From a family member's perspective (spouse or partner) one of the key concerns reported was seeing their loved ones struggling with the illness:

"*Watching him struggle is very difficult for me. I have seen him in the worst possible stages, barely able to walk, dragging his leg, he has fallen*" (Habermann 2000:1410).

Evidence suggests psychosocial and physiological disruption often resulting in a gradual decline from society and the way in which others react during episodes of sudden uncontrollable tremors or complete immobilisation. Disharmony is associated with the social stigma that exists and the lack of understanding or misconceptions of the illness creating growing psychological disturbance and discomfort for the person suffering with Parkinson's disease. From the patient's perspective alterations in body image and perceptions in relation to how individuals viewed themselves with the notion that others also viewed them in a negative way appear to have a profound effect on self esteem (Fleming 2004). Feelings of incompetence, embarrassment and 'living on edge' (disharmony) are embedded in the nature of the disease: For example a person can be made to feel misunderstood because they are unable to speak clearly or they are capable of walking one minute and not the next (Caap-Ahlgren et al 2002). These visible manifestations are a sharp contrast to people living with a haematological malignancy and the consequences of apparently looking well (4.13.1) which is also misconstrued.

5.9 Limitations

As with any research study there were a number of limitations some of which

have been addressed previously for example issues associated with the role of insider/practitioner researcher and the potential for influencing the data collection (3.9.2) In addition more specific issues relating to the study (3.9.3) have also been acknowledged such as the appropriateness of returning transcriptions to participants for clarification of meaning.

Returning to the nature of the disease, a limitation existed regarding selection of participants and the diversity or multifaceted character of myeloma and its classifications. The majority of the patients (n=14) who participated had the most common type of myeloma categorised as IgG kappa or lambda light chain myelomas. However it would not have been feasible to recruit patients with some of the more obscure or uncommon types of myeloma some of which are so rare that they represent a minute percentage of the myeloma population. For example both IgD and biclonal myelomas represent 1% of the myeloma population. The experience of illness would have contrasted with other classifications because of the different symptoms and would have enriched the study. The study could also be viewed in terms of a 'snapshot' in time as healthcare services and treatment are constantly evolving and improving.

The sample of participants (n=40) was relatively small and patients and family members were recruited from one centre. The individual groups of patients (n=17), family members (n=11) and healthcare professionals (n=12) represented small samples restricting generalisability of the study. The nature of qualitative approaches to research tend to focus more on events, circumstances and experiences with smaller numbers of participants. However, due to the restricted number of Clinical Nurse Specialists in myeloma, the healthcare professionals were recruited from various regions in the United Kingdom. The patients and families were known to me previously with the exception of six patients and two family members. This may have influenced the data collection and the way in which the participants responded while participating in the study as previously discussed in specific methodological issues (3.9.2). These interviews were more productive because of the established relationship and it became apparent, that for some of the participants, it was an emotional but cathartic experience as it provided an opportunity for individuals to discuss

'sensitive' and 'personal' issues that had a significant impact on their lives and supportive care needs.

5.10 Towards a model of supportive care

Developing a model of supportive care would seem a natural progression forward. A basic premise underpinning the model is that human beings all have fundamental needs and that nursing and healthcare are directed towards the family and not merely the individual. The Arc and Tunnel diagram (Figure 8) represents a model of supportive care in its infancy to be developed and refined further. The large arc is divided into four domains:

- Physical needs
- Psychosocial needs
- Existential and spiritual needs
- Informing and educational needs.

The central components (main interrelating concepts) of the model are healthcare, communication; supportive care needs, *Contention* and illness trajectory. The tunnel part of the diagram represents a potential illness trajectory. Each continuous black arc relates to periods of unstable or progressive disease (relapse, refractory and end of life). The first arc at the tunnel entrance labelled 'diagnosis' is situated within a three way arrow indicating potential course of direction of the disease, for example the patient may not make any progress and die shortly following diagnosis. The dotted arcs relate to stable disease or remission. Each arc equates to approximately 6 to 12 months of life. The assumptions underpinning the model of supportive care are that healthcare professionals, patients and families work in collaboration to establish their immediate and ongoing supportive care needs in light of recent policy developments (Department of Health 2007; NICE 2004). The model requires an understanding of supportive care needs and how to elicit specific information in order to identify and meet the individual requirements of a patient and family. The model can be used in conjunction with the nursing process or within a framework from other disciplines and is yet to be validated.

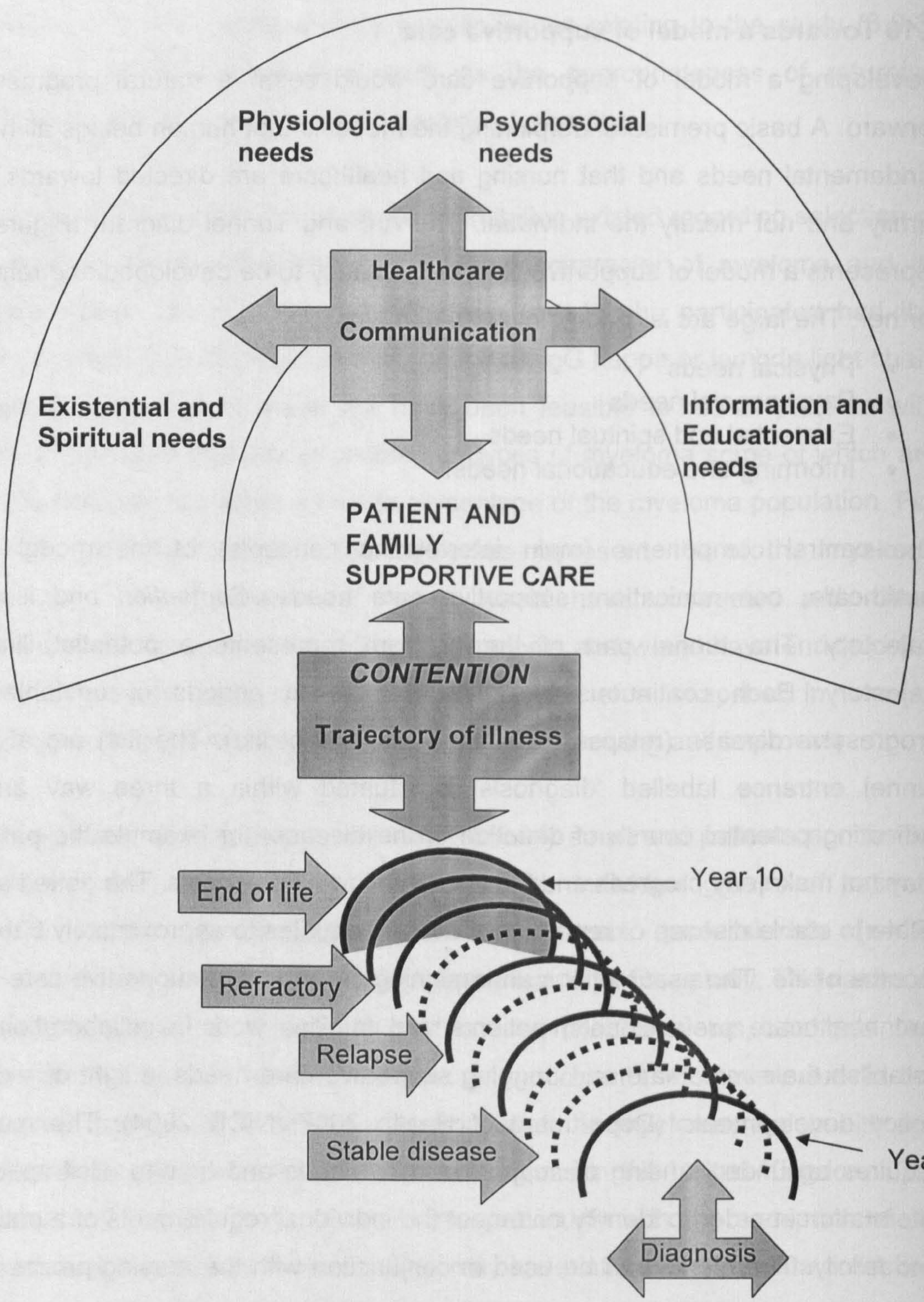


Figure 8 Model of supportive care

5.11 Summary and the emerging theory

This chapter discussed the findings of the research within the context of the core category *Contention* and associated subcategories, which have been explicated in relation to existing literature. The elementary components of the theory of *Contention* are further explicated through the undertaking of a concept analysis. The theory of *Contention* is a raw substantive and descriptive theory, which has emerged through human struggle and adversity. The overall emerging theory of *Contention* and its rudimentary components are presented within the metaparadym concepts of person, environment, health and nursing in Appendix 14. The aim of the research was to increase understanding and awareness in relation to the impact of multiple myeloma on an individual's life and explore the supportive care implications. Consequently a proposed model of supportive care needs for patients and their families has also been presented. Chapter 6 explores the issues arising from the research, their significance and contribution to the body of knowledge.

Chapter 6 Conclusion

6.1 Introduction

The aim of this research was to explore individuals' experiences and supportive care implications living with multiple myeloma, a rare, progressive and incurable cancer. The research was also aimed at complementing the increasing amount of worldwide biomedical research and clinical trials in existence. The inspiration came from my clinical practice working as a clinical trials nurse. The decision to take on this investigation was based on the assumption that healthcare professionals were not meeting the psychosocial needs of the patients. The objective was to generate theory derived from data collected from the research participants thus influencing the decision to utilise a grounded theory design. This final chapter summarises the findings and their significance in relation to the way they contribute to the body of existing knowledge. Implications for future practice, education and research are presented. Further recommendations are suggested in relation to supportive care needs of patients and their families. An overall contribution towards the body of knowledge, strategies employed for dissemination of the findings and concluding comments complete this thesis.

6.2 Findings and their significance

6.2.1 Contention

'*Contention*' represented the core or central category that emerged from this grounded theory study. The main interrelating categories comprised of 'Ways of communication', 'Nature of the disease', 'Impact on life' and 'Supportive care needs'. *Contention* was defined and explicated further through the process of concept analysis (5.3). The defining attributes of the new nursing concept *Contention* identified as struggle, battle, disruption and disharmony in the context of living with multiple myeloma were all clearly represented in the research data but not all appeared together representing a 'model case' in the literature. According to Walker and Avant (2005) a 'model case' can be constructed from real life experiences or examples found in the literature. *Contention* as a concept helps to explain the nature of the demands associated

with the diagnosis and contributes to enhancing understanding of living with a progressive disease. There is a presentation of the emerging components of the theory of *Contention* (Appendix 14). The theory, as it stands, is descriptive, not predictive or explanatory and will evolve in further research and publication through the undertaking of postdoctoral study.

6.2.2 The fundamental issues

The original aims and objectives of this research (1.10) relating to the meaning of living with multiple myeloma in terms of becoming ill and being diagnosed (4.4.2, Table 3), impact on personal or family life (4.22.2, Table 17), impact on family members (4.17.2, Table 12), impact on professional or working life (4.17.1) and perceptions of health care and supportive care services (4.24, 4.25.2, Table 19) correlate to the findings presented in Chapter 4 and discussed in Chapter 5. Delay in diagnosis, for example, represents a fundamental issue relating to the meaning of living with multiple myeloma in terms of becoming ill and being diagnosed. Complex medical language used in haematological oncology was perceived by participants (patients and family members) in terms of healthcare professionals communicating in a way that sometimes created confusion and misunderstanding. The numerous characteristic periods of relapse and remission (stable disease) epitomises the unpredictable and unrelenting nature of the disease and the emotional impact on individuals and family members. The invisible struggle is explicated in terms of impact on family life, sudden loss of income and difficulties experienced when accessing supportive care services.

The issue of delay in diagnosis (a primary cause of *Contention*) is significant because of the monumental impact this has had on the quality of life of the participants. It is known that multiple myeloma is difficult to diagnose because of the complexity and unremarkable onset of the disease. The findings from this research contribute new understanding of the ramifications of delayed diagnosis from the patient's and family's perspective. The result of undetected and consequently untreated bone disease progressed to the stage where several of the participants had broken backs (multiple vertebral fractures). It is argued, therefore, that there should be a focus on investigation of cause and not merely

treatment of symptoms based on medical judgement, biased towards the probability that the condition is a common ailment.

A fundamental issue addressed in this thesis is communication and language that is used when healthcare professionals are interacting with patients and their families. Haematological oncology is a highly specialised clinical area and healthcare professionals naturally converse in haematological terminology, which for them is familiar and routine. For many of the participants (patients and their families) a diagnosis of an incurable blood cancer was shocking and devastating news resulting in disruption and disharmony *(Contention*). The words 'multiple myeloma' represented foreign terminology and the rarity of the cancer meant that most individuals had heard the name of the disease for the first time. Interactions during this sensitive and vulnerable phase were usually emotionally demanding for the healthcare professionals and even more so for the recipients of bad news. The use of complex medical language created confusion and chaos leaving some of the participants in a state of bewilderment exacerbating their distress.

Contention escalated during periods of relapse (unstable disease) which followed a pattern of relative normality meaning reprieve from the long months of treatment with chemotherapy. This aggressive and prolonged treatment period was replaced with monitoring of stable disease and continued supportive therapy such as monthly pamidronate infusions for bone disease and analgesics for pain control. During periods of monitoring patients and their families struggled with mixed emotions and uncertainty. On one hand it was perceived as a monumental relief to return to normality, but on the other relapse was anticipated. The uncertainty was not knowing when or how long it would be before the next relapse. Participants kept a watchful eye on their blood test results especially the Mbands or paraprotein levels (disease markers). Any slight elevation created high anxiety because this indicated that the disease was probably starting to progress. Participants described living with multiple myeloma in terms of 'living with a time bomb' and 'living on the edge'. Patients who had experienced more than one or two lines of chemotherapy knew what to expect. Others who had only experienced one line of chemotherapy and were

living with stable disease appeared more optimistic in comparison. One participant who had an unusually long period of stability (remission) for several years was more shocked about the relapse than the diagnosis having believed that the cancer had been cured despite being informed that myeloma was incurable.

The invisible struggle encompassed all the characteristics of *Contention* and related to the difficulties participants experienced and the impact of the illness on family life that healthcare professionals were apparently unaware of. Finance and sudden loss of income was a major concern for participants who were no longer able to work for example. Individuals who were too unwell or disabled relied on family members to access support services on their behalf. Dealing with external agencies such as the DHSS was problematic for numerous reasons and consequently individuals either gave up through exhaustion or continued with a battle that lasted for months until the situation was resolved. The crucial point here is that if healthcare professions take the initiative in the early stages of the illness and appropriate referrals are made families will receive the help they need at the earliest opportunity and not have to struggle alone.

The progressive nature of the disease and its trajectory delineate specific points in time when *Contention* may escalate or crescendo which ultimately determines periods when emotional support for patients and their families could make a significant difference to their psychological well being and adjustment. Critical points in time are:

- Transformation of MGUS to myeloma
- Confirmation of diagnosis
- Starting treatment
- Hospitalisation
- First and subsequent relapses
- Interim phase (monitoring and uncertainty)
- Ending cancer treatment (not having any impact)
- End of life (palliative care).

The generation of findings and grounded theory produced from this research underpin the central hypothesis of this thesis explicated below:

Increased understanding and awareness of the impact of a rare, complex and progressive cancer will assist healthcare professionals in the identification of patients' and their families' individual supportive care needs at specific points in time throughout the illness trajectory.

6.3 Recommendations for practice

Findings suggest that the supportive care needs of the participants were not always recognised or addressed. Participants were not able to articulate their needs until they had time to understand and accept the implications of the diagnosis and the impact this would have on their lives. The participants in this research attended the chemotherapy day care unit and most were keen to take on responsibility for their health and well-being although there are critical points in time as mentioned previously when they may require hospitalisation or professional care. Patients and their families need to be kept well informed so they know what to expect and require adequate time to arrange their lives around hospital appointments and treatments. Each family is unique and it may not be possible to anticipate all their supportive care needs.

It was with the outpatient setting in mind and families struggling at home that the concept of a *Family Self-Assessment and Referral Plan* (Appendix 19) was developed during the course of this project. This leaflet aims to help patients and family members identify their supportive care needs and explain about the services that are available to them. It also provides contact details of their local clinical nurse specialist who may assist them or make an appropriate referral. The main objective is for patients and families to have immediate access to professional help and advice when they need it. The leaflet has been designed to be handed to the family by a healthcare professional once it has been completed with the contact details of the local clinical nurse specialist and Macmillan nurse. This may involve liaison between local hospitals and Cancer Centres when patients travel further from their homes for treatment.

The need for the clinical nurse specialist, palliative care and haematological oncological teams collaborating at an early stage of the illness is essential and must be considered whenever a person is diagnosed with this or any other

haematological malignancy. This is applicable to all patients diagnosed with cancer and other chronic debilitating and progressive illnesses.

Patients do not always have access to clinical nurse specialists who have the knowledge, expertise and competence to educate, advise and support patients and their families throughout their illness trajectory. Macmillan and palliative care nurses also have specialist knowledge and expertise relating to accessing resources in the community and helping with practical support and finance. In the absence of this specialist provision healthcare professionals need to gain the knowledge in order to provide the supportive care these patients require.

6.4 Recommendations for education

Findings suggest there is a need for healthcare professionals to acquire specialist knowledge in relation to the community and its resources available to patients and their families. With a greater understanding of these resources healthcare prefessionals can be proactive in meeting the psychosocial support needs of patients and their families. Providing educational opportunities that increase the awareness of resources available within the community is one way of increasing the heathcare professionals' knowledge. In addition secondments to other clinical areas is one approach to learning and understanding the professional roles of others.

The research demonstrates that communication between patients, families and healthcare professions was often problematic because of unfamiliar and specialised terminology used in haematological oncology. This often resulted in confusion and anxiety. Specialist communication skills workshops may encourage healthcare professionals to avoid use of complex medical terminology when interacting with patients and their families. Furthermore findings suggest the complexity of the illness and its associated specialised terminology created problems for parents who needed to explain to their children about the illness and what was happening. Educating parents, therefore, would prepare them in order to communicate more effectively with their children. Gaining knowledge about the disease, how the illness is managed and guidance relating to communicating with their children will enable

parents to articulate explanations in terms that a child can understand. Parents need to be able to explain to their children how the illness is affecting their lives. This may help families to adjust and prepare their children for potentially disturbing events such as hospitalisation or alterations in appearance such as sudden weight gain due to steroids, the insertion of a central venous line or hair loss.

Findings suggest that the rarity of the disease, the complexity of its name (multiple myeloma) and lack of awareness in the public domain and other healthcare areas indicates the need for wider dissemination and provision of education leaflets explaining about the disease, its progressive nature and its implications. In the absence of media coverage, educational leaflets could help to increase awareness and understanding in other areas or departments of health, social care, community and in the workplace. From the GP's perspective dealing with the rarity of the disease, findings suggest that assumptions were apparently based on what they (GPs) normally expected to find. Back pain, for example was often assumed to be a strained muscle or a slipped disc. It is recommended that a move towards educating GPs to focus on all potential uncommon and common diseases with the undertaking of prompt investigation to identify the origin or cause of illness needs to be considered as mandatory and standard practice.

6.5 Recommendations for research

The following research recommendations relate to the findings of this grounded theory research: ways in communication, nature of the disease, impact on life and supportive care needs. The research findings are summarised within a framework of integrated conceptual hypotheses (Appendix 9) contributing towards understanding the nature and impact of the disease and direction for further research (Glaser and Holton 2004). The direction recommended from this research is:

- An investigation into delay in diagnosis and further exploration of the impact that delay has on the quality of life aimed at providing substantial evidence to suggest the need for changing medical practice and highlighting strategies towards early detection.

- A study that aims to answer the question: Is the shock of a cancer diagnosis such as multiple myeloma considered potentially further exacerbated because of its rarity, incurability and progressive nature?

- Exploration of the issue of the way in which healthcare professionals communicate and give information in the haematological oncological arena where the language is specialised; how that informaiton is perceived by the recipients and determine whether or not this impacts on individual's decision making capabilities when newly diagnosed.

- A study that aims to provide an operational definition of the concept *Contention* involving identification, exploration and measurement of the phenomenon. Measurement requires a tool that accurately reflects the defining attributes of the concept.

- A study to explore the concept of *Contention* in relation to illness trajectory and chronic diseases.

- An investigation into the effectiveness of treatment for multiple myeloma verses the serious, prolonged or irreversible adverse events associated with medication or chemotherapy used to answer the question: Does treatment improve or impede quality of life?

- An exploration that highlights the impact of the disease, its treatment and associated impact on sexual relationships and what healthcare professionals can do to help individuals express their concerns and initiate approprate referrals.

- A study that determines whether healthcare professionals are doing enough to help parents communicate more effectively with their children when living with a complex and progressive cancer.

- An investigation into perceptions of whether family members are more supportive when visible signs of illness or disease are apparent and when individuals appear to look 'normal and healthy' despite the presence of disease, whether this is generally perceived as 'normal and healthy'.

- An investigation into perceptions of employers and working colleagues or associates towards absenteeism associated with illness: Reactions in the work place and how supportive colleagues or associates are in the working environment.

- An investigation into perceptions of supportive care services from the patient and family perspective.

6.6 Overall Contribution

This grounded theory study provides insight through exploration of individuals' life experiences living with a complex haematological malignancy that is poorly understood impacting on healthcare professionals and the provision of supportive care. This study contributes to the body of knowledge in the following ways:

- A unique nursing concept (associated with the experience of living with multiple myeloma) named '*Contention*' has emerged and developed from this grounded theory

- Increased awareness and understanding of multiple myeloma and the impact that the disease has on the individual and on family life

- Identification that it is important that patients, families and healthcare professionals collaborate to identify supportive care needs at specific times along the illness trajectory to inform service provision and develop effective care pathways.

6.7 Dissemination of results

Dissemination of the findings (emerging key issues) commenced soon after data collection started as the ongoing analysis immediately followed each data collection and return of transcribed interviews. Poster presentations have been accepted and exhibited locally and internationally. Numerous oral presentations have been given locally and nationally. Through further publications and future presentations, the findings will continue to be effectively disseminated. Summarised versions of the results have been distributed to participants and colleagues. The most recent local presentation took place at a regular evening seminar for the medical oncology team and cancer nurses (April 2009). A donation of the completed thesis will be contributed to the 'Steinberg Collection' at the RCN Library in London and to the Myeloma UK organisation.

6.8 Concluding remarks

Undertaking a PhD is a steep learning curve and one which made me realise that there is so much more to explore and learn. This grounded theory has contributed to enhancing understanding of the impact of a relatively unknown

cancer that is progressive, debilitating and unrelenting. More importantly people with uncommon cancers or diseases have the same human needs that people with common cancers or diseases have. All persons are equally important whether well or unwell and every individual's supportive care needs should be acknowledged. As healthcare professionals it is our responsibility to probe more deeply and reassure patients that we can help them by meeting all their needs. 'Chair-side' nursing on the chemotherapy day care unit should not focus entirely on treating the disease when the impact on life is immense and affects the whole family. This study offers insights into the *Contention* that underpins the experience of living with multiple myeloma, and the challenge facing healthcare providers seeking to provide effective supportive care. Other cancers will also evoke *Contention* but multiple myeloma requires to be better understood in order to minimise the many struggles associated with it.

"So really you kind of feel like you're living on 'Death Row' I suppose because you don't know, you think things ... are OK and then suddenly something happens...I struggle a bit" (Fred P 017).

"*The fight is to sustain life, it's as simple as that, that is the fight*" (Frank P 007).

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Appendices

Appendix 1 Chair-side nursing – The impetus for the study

The researcher's perspective

I feel it's important and pertinent that the researcher's perspective and the impetus for the study is taken into account because without the experience of working on the chemotherapy day care unit and looking after patients with multiple myeloma (bone marrow cancer) I would not have undertaken this project. Chair-side nursing is a term that came to me while working on the chemotherapy day care unit as a clinical trials nurse. The chair is a reclining armchair, which can be extended allowing the patient to rest with feet up if required while being treated with chemotherapy or receiving blood transfusions. Since the late 1960s when my nurse training began I have from time to time experienced nursing sick and dying patients in bed and the idea of people coming to a day unit and sitting in armchairs for two, three or up to several hours while receiving treatment was at first quite extraordinary. My official role title is clinical trials coordinator and I prefer to use the term clinical trials nurse because that is what and who I am. The majority of trials I have been involved with relate to single and combined chemotherapy agents for patients with multiple myeloma. Although the nature of the work lends itself to huge amounts of necessary administration with a focus on data collection and record keeping there is also a large nursing component. First and foremost I will attempt to draw a picture of the working environment, the place, the patients and hospital staff who inspired me to undertake this study.

The chemotherapy day care unit

The general layout of the chemotherapy day unit as shown in a diagrammatic scheme in Figure 1 is one that when filled with people and equipment leaves no room to swing a cat and manoeuvrability can be extremely difficult. This not only creates frustration for the staff but ethical dilemmas for example privacy and confidentiality can become compromised. The atmosphere is very changeable and ranges from different levels of stress and sadness to much lighter modes of interaction between staff and patients. Laughter for example is often heard. Healthcare professionals working in the haematological oncology field appear caring and sensitive to the needs of the patients especially during periods of despondency. Because of the nature of illness long-term relationships are established between staff and patients lasting (in some cases) for several years. Many patients are on borrowed time so there is an emphasis on treatment starting promptly at the critical moment when disease is progressing following a period of stable disease or remission. Consultants and registrars appear directly approachable and accessible to the patients by telephone, e-mail or make themselves available in person when the patient attends the clinic or the day unit without having made an appointment.

Patients are treated for leukaemia, lymphoma, multiple myeloma, other haematological malignancies and red blood cell disorders. There are approximately 30-40 ongoing clinical trials and despite this number those patients participating only represent a small percentage of the patients attending the day unit. A clinical trials team will specialise in a particular area for example the trials relating to lymphomas will have a separate clinical trials team to that of multiple myelomas. The clinical trials team consists of the consultant or registrar, nurse, pharmacist, and a monitor (clinical research associate) who checks the accuracy of the data that has been collected and recorded (source verification). During the day on the unit there may be four clinical trial nurses, six day unit nurses, four day unit doctors, one receptionist, and one domestic, (there are variations in numbers of staff which can get much smaller or fewer). There are two white working boards hanging on the wall near the nurse's treatment room. The large board usually has a long list of patients' names who are expected to attend and do not include those who are referred from the clinics, or those who just turn up unexpectedly. The work is divided up and patients are allocated to a specific nurse whose name also appears on the board along side that of the patients they are expected to look after. The smaller board consists of short lists of clinical trial patients, and patients having special procedures such as bone marrow biopsies or collection of peripheral blood stem cells for harvesting (apheresis). The large white board is central to the organisation of the work and is used as a gathering point for the day unit staff at certain times of the day for updates and communication.

Dual role of nurse and researcher

The boundaries that normally exist between the roles of researcher and nurse appear to over lap, which makes this particular post (clinical trials coordinator) unique. This is partly because clinical trials in oncology have become the norm and there is no treading on anyone's toes. Being there as a "research person" is acceptable and it is implicitly understood that while attending to the patient I take on the responsibility of a trained nurse because I am invariably looking after very sick people. Patients living with multiple myeloma may arrive on the day unit depressed, distraught or extremely ill and barely able to walk. In these circumstances the role of the nurse supersedes that of the researcher and research activities or "run of the mill" things are put on hold.

In a previous job working as a clinical trials coordinator in thrombosis research involved with trials which focused on prophylaxis for patients undergoing hip and knee surgery, I was made to feel like an intruder and was not very welcome on some of the hospital wards. One ward sister finally accepted my presence when she saw that I was prepared to stop collecting data and get someone a bedpan. The fundamental difference between oncology and thrombosis trials is one aims to extend the person's life while the other aims to reduce the risk of deep vein thrombosis following surgery, which could potentially lead to a fatal pulmonary embolism. The fact that some of the trial medications are considered to be experimental has no bearing in the field of oncology where it may be looked upon as a potential miracle cure or at best another reprieve.

Patients are informed of the treatment options. With advice from the haematologist they can choose between not participating in a trial and receiving

a standard or traditional therapy, or participating and receiving a new combination of standard therapies, or participating and receiving a completely new therapy (unlicensed drug). Some patients simply run out of options having had several lines of conventional therapy and the only path left open will be the new treatment. Spending much of my time on the day care unit administering chemotherapy to the patients has meant that I have become part and parcel of the day unit staff although my role is that of a "research person". Wearing a nurse's uniform was something I deliberately chose to do so I could "blend in" and not feel like an "outsider" and it was important that I did not appear to be different from my nursing colleagues working on the day care unit. It also prevents any confusion as to who I am (a patient I met for the first time wanted to know if I was a "proper nurse" because I was not in uniform). Furthermore there are the practical aspects of the job, issues of hygiene, infection control, health and safety when obtaining blood samples or handling cytotoxic drugs and the need to wear protective clothing.

Attending the chemotherapy day care unit

Patients coming to the day care unit for the first time are usually apprehensive. They and their families are not only coming to terms with the diagnosis of cancer but are trying to get used to the idea that they are going to receive some form of treatment and this will mean making changes to their normal routine. A newly diagnosed patient is given huge amounts of verbal and written information in a short space of time often during one or two visits to the clinic. This can be extremely overwhelming for some while for others it is welcoming and reassuring. This can cause high levels of anxiety because of the adaptations they must make to their lives. It can be particularly stressful when patients have dependants prior to the onset of the illness, young children, elderly parents, or a spouse who needs care and would normally rely upon them. Receiving cycles of intravenous chemotherapy may involve travelling to the day unit twice a week for two out of a three-week cycle. Other supportive care may be required between treatments such as blood transfusions or iron infusions. The illness, the treatment, and the travelling can cause extreme tiredness and fatigue. Getting to the day care unit, receiving the treatment, and getting away to spend the rest of the day doing normal things becomes the main objective, even if this means resting for long periods at home. The main focus for all patients is whether or not the treatment is working. Newly diagnosed patients often assume that this will be so but for those who are "fully trained" that is they have already received several lines of therapy know that this is not always the case and are familiar with the unpredictable path of the disease and it's response to treatment.

The paraprotein levels found in the blood or the urine are the markers that inform us as to whether the patients are responding to the therapy or not. Although there is always an exception almost all of the patients will take a keen interest in the blood test results and will want to know what the paraprotein levels are at the end of each treatment cycle. This causes huge excitement when the levels have dropped significantly, and huge disappointment when they are rising or at a standstill. Rising is a sign of disease progression and remaining at the same level over a period of time implies that the therapy is not working. Waiting until the following cycle which could be three or four weeks

plus the time of several days before the test results are seen means that a patient may be on "tender hooks" for more than a month not knowing whether or not the treatment is having any effect. Patients *appear* to pick themselves up again and respond to reassurance, encouragement, support, or some optimism from a nurse, a doctor, or a friend. It may be a small remark such as "it's only risen very slightly, we are just as likely to see a decrease after the next cycle of treatment. Lets just wait and see".

Making assumptions

I use the word *appear* because we (healthcare professionals) make many assumptions about what we think the patients are going through and what it must be like for them. In reality we cannot possibly know what it is like and how the illness is affecting them and their lives or that of their families. The chemotherapy day care unit is often crammed full with people. Nurses and doctors are seen walking backwards and forwards. Nurses are cannulating patients, taking blood samples, or setting up infusions. Doctors are examining patients; phones are ringing constantly; bleeps are bleeping; patients are having treatments or they are waiting to be seen. Patients are treated and then go home. Alternatively patients become too ill to go home and are transferred to a ward. Amidst the hustle and bustle of the day care unit environment one patient waiting may start shouting or burst into tears and it is not until there is such an emotional outburst that anyone is aware that there is something wrong. Some patients remain quiet while waiting to be seen, while others talk together often about their illness, their treatment, and whether or not they feel they are making any headway. There are patients who will tell a nurse without being questioned that there are problems such as the physical side effects from the medication (chemotherapy), or that they have depression. Sometimes patients do not want to make a fuss; they see how busy the nurses and doctors are, and as a result of this they remain quiet. It cannot be assumed that there are no problems. Patients participating in clinical trials are usually keen to report any side effects or adverse events because they appreciate the importance of collecting information and how it will affect future patients and the way in which they are treated.

It was an emotional outburst from a female patient that made me sit up and think about my clinical practice and made me realise that I had made the wrong assumptions about this particular lady. It was a very busy period of time and I had seven patients waiting to be seen on the day care unit. Unless I have to prioritise as in the situation that someone is suddenly feeling very unwell and requires immediate attention I work on a first come first serve principle although appointment times are arranged in advance people cannot always make it in time. So the aim is to get through things as swiftly as possible bearing in mind that people are waiting to be seen. I had observed that this patient was becoming more demanding over a period of weeks. She would come and find me on the unit and make sure that I was aware that she had arrived. This would be followed by an occasional nod of the head if I happened to look in her direction. I remember thinking about her profession (teaching) and although she had retired I had decided that she was assertive and autocratic to the point that she was accustomed to making demands. She stopped me in mid flight trying to avoid her and asked how long it was going to be before she could have

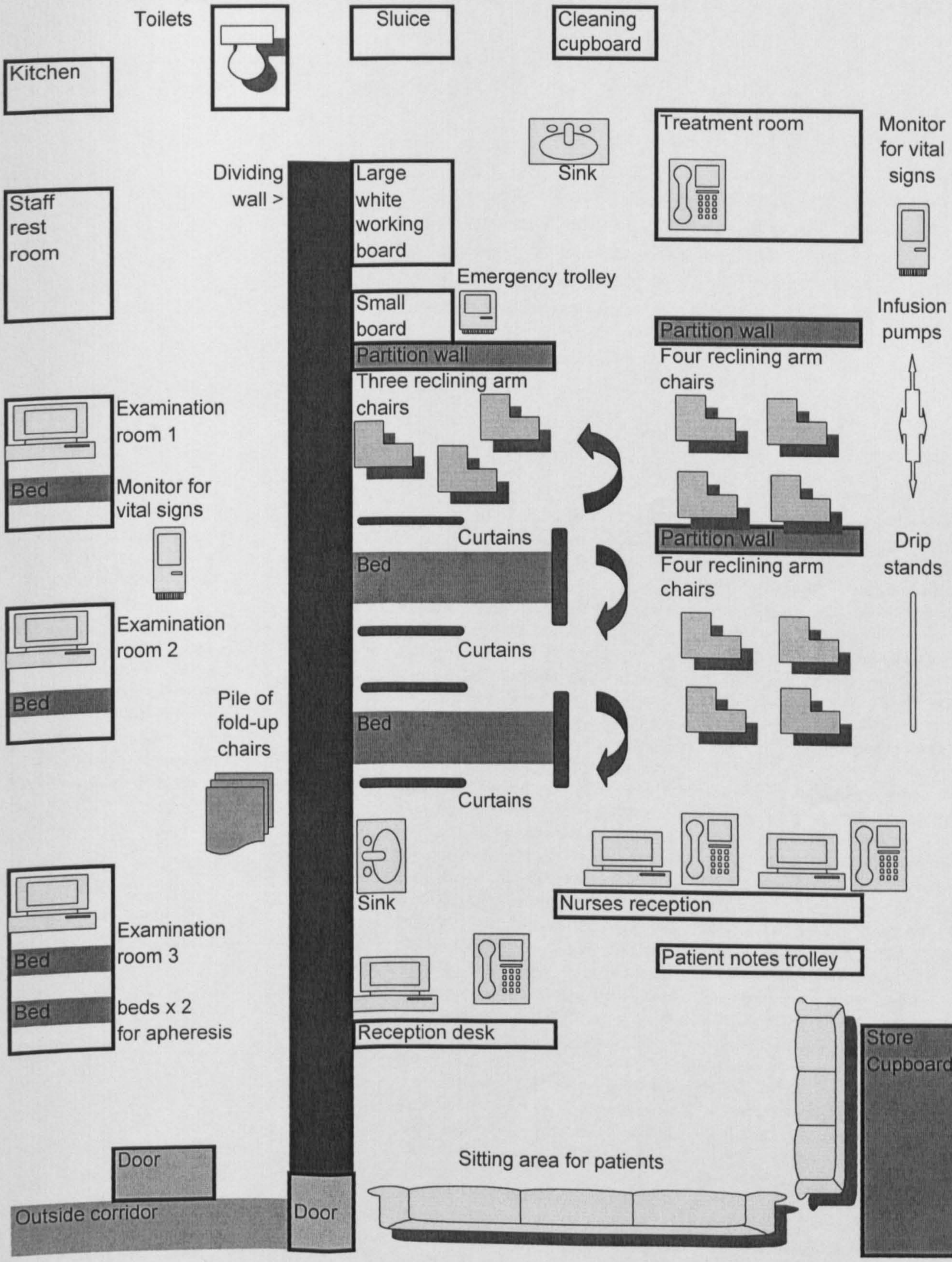
her treatment. I apologised stating that there were other patients waiting. She started to cry. She apologised for her attitude towards me and continued to cry. I stopped a patient going into the only free examination room to wait for the doctor. It was inside this room with the door closed that this lady shared some of her life experiences living with her husband who had Alzheimer's disease. He had stood on the doorstep of their home that morning shouting, "where the hell do you think you are going?" She answered "to the hospital and I will be back as quickly as possible".

If we (healthcare professionals) do not know what is going on in people's lives how can we help them? If we do not know what is going on how can we understand why they are behaving in a certain way? How in turn do we become more sensitive to their needs? It might well be that a person will not wish to share these life experiences with healthcare professionals and on the other hand patients who do want to share their experiences and emotional problems may not have the opportunity to do so. The kind of environment in a chemotherapy day care unit may not be conducive because it is open planned with reclining chairs almost touching one another; spaces crammed full of people and examination rooms constantly in use.

Assumptions are usually made based upon the outer appearance and what people perceive as normal. Patients with multiple myeloma often appear to look well which can be deceptive and because of this are able to camouflage or hide behind their true feelings when necessary. For example one male patient stated that he could not tell his elderly parents that he has cancer and has so far kept it from them. A female patient disclosed that she had been invited to a formal luncheon and her one fear was that she might have to take a wheel chair. Another example, which heightens the layperson's perception, was brought to my attention while booking hospital transport for a patient. A member of the transport department informed me that there was no room for the patient's husband who always accompanied her when she came to the day care unit for chemotherapy. The member of staff working in the transport department stated that the patient always looked well and did not require an escort. The issue was quickly resolved following a discussion with the manager of the department. However the situation highlighted the fact that there are people employed within the hospital environment who have regular contact with patients and their families, and who have little or no knowledge of the illness and it's implications. It can be argued therefore that there is a lack of understanding and sensitivity towards patients and their families within the hospital environment because of this.

Figure 1

Diagrammatic scheme of the chemotherapy day unit



Appendix 2 Publications

Multiple myeloma: understanding the impact of the disease

Abstract

Multiple myeloma is a cancer of the red bone marrow and despite modern treatments, such as high dose chemotherapy and stem cell transplants, it remains incurable with a median survival of between three to four years (Hoffbrand *et al* 2001, Bradwell 2003). The aim of this article is to increase awareness and understanding of this relatively unknown cancer.

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- xxx
- xxxxxx
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Multiple myeloma is a disease which is often difficult to diagnose and difficult to treat. An overview of the disease will include clinical features, diagnosis, treatment options and likely outcomes. A case study will help to illustrate the impact of the disease on the individual.

Multiple myeloma can be simply described as bad blood and fragile bones. It is a haematological malignancy or bone marrow cancer that produces excess amounts of plasma cells, osteolytic bone lesions, and the appearance of monoclonal proteins that may be seen in the blood or urine. Plasma cells normally produce immunoglobulins (Igs) or antibodies. In multiple myeloma the cloned plasma cells (myeloma cells) produce monoclonal Igs. These appear as a spike in the blood serum test called the M Band or Paraprotein level. Normally there is only 1 per cent plasma cell content in the bone marrow. This increases to 30 per cent and can be more than 90 per cent in multiple myeloma (Bradwell 2003).

The invasion of myeloma cells (cloned plasma cells) results in a significant reduction in the normal production of plasma cells. This leads to a compromised immune system that can result in recurrent infections. The most important differential diagnosis is a condition known as monoclonal gammopathy of undetermined significance (MGUS) which means a paraprotein level exists in the absence of multiple myeloma. This can, however, transform into multiple myeloma or other associated diseases, for example lymphoma, amyloidosis, in 26 per cent of patients (Singer 1997).

Common clinical features of multiple myeloma are: bone pain and pathological fractures; anaemia and bone marrow failure; renal impairment; infection due to immunodeficiency and neutropenia. Less common clinical features are acute hypercalcaemia; symptomatic hyperviscosity; neuropathy; amyloidosis and coagulopathy (Singer 1997).

Multiple myeloma represents only 1 per cent of all cancers. It is diagnosed in 3,500 people each year and there are approximately 10-15,000 people living with the disease in the UK (King 2003).

Most patients are aged over 40 years at diagnosis. In recent years, there has been an increase in the number of younger patients. It is now known that the median age of 63 years has decreased (Schey and Pallister 2004).

Myeloma is more common in the Afro-Caribbean ethnic groups than Caucasians or Asians, but is present in all ethnic groups, with a higher incidence in males.

The cause of the disease has not been identified but certain contributory factors may be associated with myeloma. These are: genetic factors; weakened immune

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system; exposure to particular chemicals; radiation and viruses (Morris 2003).

Myelomas are usually described in terms of secretory and non-secretory, symptomatic and non-symptomatic or smouldering. They are also classified according to the types of immunoglobulins (Igs) and the presence of light chain or heavy chain disease. The structure of each Ig molecule is made up of two heavy chains and two light chains. The Ig molecule itself is normal but sometimes these are altered due to disease or separated resulting in a rare heavy chain disease or the more common light chain disease. Light chains are also known as Bence Jones proteins. There are two types of these called Kappa and Lambda. Only one or the other is present. The monoclonal protein or paraprotein level found in the serum is IgG in two thirds of the population of myeloma patients; IgA in one third; and IgM, IgD or IgE are rarely found but can exist on their own or coupled together. The urine contains Bence Jones protein (Kappa or Lambda free light chains) in two thirds of the myeloma population and in some cases is present without a serum paraprotein (Hoffbrand *et al* 2001).

People diagnosed with multiple myeloma are likely to experience a number of physical and emotional sequelae that may be as poorly understood as the disease itself. Sirohi and Powles (2004) describe the activity of the disease as 'intricate interactions which occur between the bone-marrow microenvironment and the myeloma cells, frequently causing bone destruction which in turn stimulates tumour growth'.

A number of bones can be diseased with myeloma cells but this is not something that can be seen or detected easily unlike other cancers. It has an unpredictable path with numerous periods of relapse and remission. A patient can die within days or weeks of being diagnosed on one hand and on the other can live for many years with a 'smouldering' myeloma that does not require any medical intervention (Bradwell 2003).

Diagnosing multiple myeloma

Diagnosing multiple myeloma is difficult. In its early stages it is often asymptomatic and early symptoms are usually very non-specific such as lethargy, mild anaemia or back pain. According to Watts (2005), 'myeloma is a victim of its own rarity – difficult to diagnose, and even harder to treat, devastating for sufferers and their families, yet poorly understood by both the public and many doctors'.

The disease has previously been referred to by other names such as paraproteinaemia, dysproteinaemia, immunoglobulinopathy and myelomatosis (Hoffbrand *et al* 2001, Schey and Pallister 2004) which can add to the confusion. Diagnosis is usually based on the presence of a paraprotein 'spike' (monoclonal protein or M Band) in the serum or urine sample, the presence of lytic bone lesions and more than 10 per cent plasma cells in the bone marrow.

Treatment options

Patients with symptomatic myeloma are usually treated with chemotherapy. Medical intervention prior to the onset of symptoms has not proved to be beneficial (Hjorth *et al* 1993; Riccardi *et al* 2000). Single agents such as melphalan or cyclophosphamide are usually used to treat the disease initially. They are sometimes used in conjunction with prednisolone or one of the common combination chemotherapy regimes, for example Vincristine, Adriamycin and Dexamethasone (VAD).

High dose therapy and stem cell rescue (autologus stem cell transplant) is recommended in newly diagnosed patients up to the age of 65 years and may be considered in patients older than 65 in the absence of any serious co-morbidity (Smith *et al* 2005).

The drug Thalidomide was reintroduced for treating multiple myeloma in 1999 (Schey and Pallister 2004, Weber 2004). Velcade, which started out as PS 341 and known as Bortezomib, is a proteasome inhibitor that acts by interfering with the growth of myeloma cells. Due to the drug's expense, it is currently only available in clinical trials. It has been available on a restricted named patient basis at the discretion of the haematologist and pharmaceutical company.

The aim of the treatment is to slow down the disease's progress, the outcome of which may be a partial, complete, or no response to therapy; control the symptoms and improve the patients quality of life (Morris 2003). Treatment is aimed at reaching a 'plateau phase' where the paraprotein level falls significantly and remains at that level maintaining stabilised disease; or for the paraprotein level to fall to zero when the patient enters a remission period. Many patients are entered into clinical trials and have the option of receiving novel single and combination therapies. Radiotherapy is used for lytic lesions which are at risk of or have fractures and is highly effective in treating local symptoms such as bone pain or spinal cord compression (Hoffbrand *et al* 2001). Bisphosphonates such as clodronate and pamidronate are also given to control bone disease, hypercalcaemia, and may have anti-tumour effect (Cavenagh and Croucher 2004). Transfusions or erythropoietin which stimulates red blood cell production are given to treat anaemia.

Case study

John, 38, was diagnosed as having monoclonal gammopathy of undetermined significance (MGUS) in 1998. In 2000 he started to get back pain which

gradually became almost unbearable. A few months later John had a CT scan which showed multiple lytic lesions; a bone marrow aspirate showed a plasma content of 40 per cent; serum paraprotein level of 47 (normally there is a level of zero). Bence Jones proteins were also present in his urine. He was diagnosed with IgG Kappa multiple myeloma.

John was treated with radiotherapy to his thoracic spine which relieved the pain. He commenced treatment as an outpatient with combination chemotherapy consisting of VAD. The VAD was interrupted and postponed twice due to hospitalisations because of febrile neutropenia and pneumonia. He completed combination chemotherapy and had high dose Melphalan and a stem cell transplant. Following treatment he remained well for almost two years and returned to work. In 2002 he relapsed and was treated with combination chemotherapy. On this occasion John had Cyclophosamide, Thalidomide and Dexamethasone (CTD) as the Vincristine had previously caused some peripheral neuropathy. This was followed by high dose Melphalan and a second stem cell transplant.

Several months later John relapsed again with a rising paraprotein level and prescribed a clinical trial drug PS 341 (Velcade). His myeloma did not respond and instead of having a decreasing paraprotein level it rapidly rose from 30 to 70. He was taken off the PS 341 after two treatment cycles and was again treated with CTD.

John's remission lasted for a few months during which he remained fit and was able to work and socialise. In October 2003 he became a man who no longer looked well, had a pale yellowish tinge to his skin and was unable to walk without the aid of a walking stick. This was a marked transformation from the tall, slim, healthy looking man who walked into a room without effort a few months previously. He had a history of worsening back pain which was making his walking very difficult. He was treated with more radiotherapy to his spine, more Thalidomide and Dexamethasone.

Following several weeks of treatment John was admitted to hospital with a six-day history of worsening constipation, abdominal distension, malaise and anaemia. He received frequent platelets and blood transfusions. His liver function tests were abnormally deranged and innumerable new myeloma lesions were seen on his kidney and liver scans. During his hospital stay he reported numbness in his lower limbs.

An MRI scan showed an extensive extra dural mass lying predominantly posteriorally to the spinal cord extending along several of the thoracic vertebrae and the cord was found to be compressed.

Although his paraprotein levels remained low with the current treatment, the changes on the scans suggested that there was extra medullary relapse. He appeared to be making progress and was transferred to another hospital for intensive physiotherapy. John had been there for one day when he fell. As his left leg gave way, he knocked his arm against a table which led to a fracture of his left humerus. He was taken by ambulance to an orthopaedic hospital for surgery where a nail was inserted. John returned to his local hospital looking pale and weak.

John remained in hospital for three months with numerous problems including chest pain, cardiac arrhythmias, intermittent fever, general bone pain, and small haemorrhages from the nose and mouth associated with low blood platelets. His condition deteriorated at a steady pace. The myeloma had reached advanced stages of the disease and was no longer responding to treatment.

John prepared himself for the news that the treatment was no longer effective. The decision was made to stop treatment. The myeloma was in its terminal phases. Frequent blood transfusions were having little or no effect. John was no longer able to stand without support and had difficulty in breathing. In March 2004, arrangements were made for John to be transferred to a hospice where he died three weeks later.

Discussion

Multiple myeloma can be conceptualised as a chronic illness affecting adults from all age groups. It is different to other cancers in a number of ways:
a) it is a haematological malignancy
b) there is the presence of significant bone disease and associated functional problems
c) there is a median survival of between three to four years
d) there is no cure.

John's case study illustrates the impact of the condition on the life of an individual person. The management of the disease is often fraught with difficulties such as finding effective solutions for the prevention and control of side effects associated with the chemotherapy used to treat the myeloma. Finding an effective treatment for the myeloma itself is often a significant feature that might only be achieved through persistent trial and error. Multiple myeloma is often referred to as being in a state of relapse or refractory which means it is not responding to treatment.

The unpredictable path and numerous periods of relapse and remission are typical as seen in the above case study. There is a clear pattern of disease progression, followed by treatment, a period when the patient is well and able to lead a relatively normal life. This process may repeat over and over again. Only as the disease progresses, and enters the more advanced stages, does the quality of life become

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noticeably poorer. Remission periods may also be much longer for some patients. One female patient, from the author's (PJS) clinical practice area, had a 12 year remission following her first treatment with chemotherapy; however, this is unusually long.

It is not uncommon for patients to look perfectly well when they attend the chemotherapy day care unit for treatment. Rupert (1987) describes myeloma as 'assault from within' implying that it cannot be seen externally. People's body image may however be altered because of steroids and, although an unpleasant bloated appearance is likely, this is usually a temporary alteration. Alterations in appearance such as significant loss in height can be devastating as this is irreversible. Osteolytic bone lesions cause pathologic fractures and reduced mobility (Cavenagh and Croucher 2004). Some patients are unable to walk because of bone lesions and fractures in the pelvis and thigh bones.

A patient suffering with back pain or discomfort is extremely common in multiple myeloma. Collapsed vertebrae and spinal cord compression are seen in many patients. Back pain or backache is a common ailment and often the first symptom that patients present with. However, many people complain of 'bad backs' and may attend the GP practice several times before it is investigated further. Often patients attend the hospital for other conditions when abnormally high protein or calcium levels are detected in the blood which may alert the doctor towards the possibility of the presence of myeloma. John's abnormal monoclonal protein levels were detected while having routine blood evaluations.

The time of diagnosis is usually described in terms of a shock for most people and their families (Thomas and Retsas 1999, Maliski *et al* 2002). Many are completely traumatized and in a state of bewilderment (Davis 2002, Persson and Hallberg 2004).

Patients with multiple myeloma not only have to come to terms with a diagnosis of cancer, but they also have to take on board the additional bad news that there is no cure. Reassuring patients that multiple myeloma can be treated and having a positive attitude is very important (Bulsara *et al* 2004).

Conclusion

The NHS Cancer Plan (2000) and the NICE Guidance on Supportive and Palliative Care (National Institute for Clinical Excellence (NICE) 2004) both set out to improve supportive and palliative care for adults with cancer.

Key topic areas include: communication, information, coordination of care, psychological, social and spiritual support.

For a variety of reasons patients may not always get the support from family and friends that they need. Many patients are unable to speak to their family and close friends about how they are really feeling because they do not want to upset them. As a result of compromising, anxiety levels are increased at the detriment of their own stress (Nason 2003).

A preliminary recommendation for practice is the importance of accessible psychological support. Patients who suffer with anxiety do not always have immediate access to professional support. It is suggested that psychosocial support services are needed to cover all areas within the hospital environment and the community. It is also suggested that day care units include an 'on the spot' patient and family counselling service to meet recommendations specified regarding supportive care (NICE 2004).

Liaison and communication between hospitals is vital at all levels and needs to be followed through. Face-to-face communication is not always possible and written information in the form of hospital letters/electronic records concerning patients need to be followed up with emails and/or telephone communications. Continuous liaison between hospitals and hospital departments is a way of ensuring that relevant clinical staff are fully informed of the patient's condition when receiving treatment at other hospitals.

In conclusion, this article has described the features of multiple myeloma and explored the individual suffering associated with it. Increased understanding into the impact of this particularly debilitating disease will determine the way forward in developing future management strategies in relation to the supportive care needs of multiple myeloma sufferers and their families

Implications for practice

Future qualitative research studies should focus on exploring the experience of living with multiple myeloma from the patient and family perspective with the following aims and objectives:

- To increase awareness and understanding of multiple myeloma
- To increase awareness and understanding of the impact that the disease has on an individual's personal, family, professional or working life
- To increase awareness and understanding of the impact of multiple myeloma on significant others (family members, friends or partners)
- Development of future management strategies for planning high quality and effective care pathways in this patient group
- Identification of supportive care needs and development of supportive care assessment methods and tools
- Testing of rehabilitation and supportive care interventions.

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A FAMILY'S EXPERIENCE OF COPING WITH MULTIPLE MYELOMA

Patricia Smith, Carol Cox

Multiple myeloma is a cancer of the red bone marrow that produces excess amounts of cloned plasma cells, osteolytic bone lesions, and the appearance of monoclonal proteins that may be found in the blood serum or urine. The aim of this article is to heighten awareness of this condition and provide some insight into the often aggressive nature of the disease within the context of end-of-life care. The narrative content portrays a vivid story of a dying mother, Susan, and how the family coped with the illness and impending death. The family had little time to come to terms with the diagnosis of cancer before Susan died. There is a definite need to increase understanding of the impact of this debilitating and incurable bone marrow cancer and to strengthen the evidence base for managing the disease in order to provide more supportive care. Conflict of interests: none

Coping strategies
Dying
Impact on family life
Multiple myeloma
Unrelenting disease

This article highlights an uncommon cancer that is relatively unknown within the context of end-of-life care. It presents a small part of an ongoing qualitative study that was commenced by the first author in October 2005 entitled 'Living with multiple myeloma: a study to explore patients' experiences and supportive care implications'. The aim of this article is to heighten awareness of multiple myeloma and provide some insight into the often aggressive nature of the disease. An illustrated account of multiple myeloma is followed by the background story of a mother who was diagnosed with this incurable bone marrow cancer. The names have been changed to maintain confidentiality of the patient, the informant and the family.

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Context

The narrative in this article describes the experiences of Marian, one of the family member respondents from the first author's ongoing qualitative study. She describes how her mother, Susan, became ill with an aggressive form of multiple myeloma and died within a few months of diagnosis. The interview was recorded and took place in a quiet room at the university 6 years after Susan's death.

The impetus for the qualitative study came from the first author's experience of working in a chemotherapy day care unit, treating patients with multiple myeloma participating in clinical trials. Ethical approval for the study was granted in August 2005 by the local research ethics committee. The aim of the ongoing study is to explore: the meaning of living with multiple myeloma in terms of becoming ill and being diagnosed; the impact on the participant's personal or family life; the impact on other family members; the impact on the participant's professional or working life; and participants' perceptions of health care and supportive care services.

Multiple myeloma

Multiple myeloma is a complex and diverse haematological malignancy that is poorly understood. It is cancer of the red bone marrow that produces excess amounts of cloned plasma cells (*Figure 1*), osteolytic bone lesions and the appearance of monoclonal proteins that may be seen in the blood or urine. Plasma cells normally produce antibodies called immunoglobulins (Igs). In multiple myeloma the cloned plasma cells (myeloma cells) produce monoclonal Igs that appear as a spike in the blood serum test called the M-band or paraprotein level. Normally there is only 1% of plasma cell content in the bone marrow. This increases to 30% and can be over 90% in multiple myeloma (Bradwell, 2003).

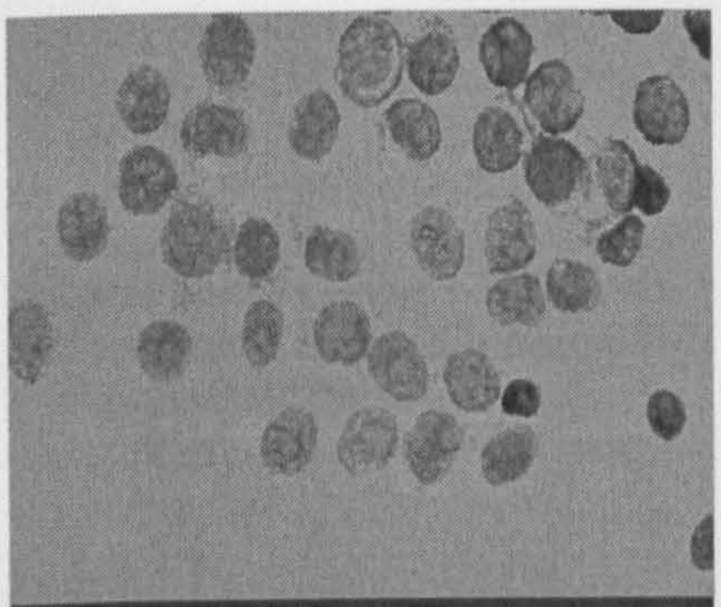


Figure 1. Bone marrow smear showing myeloma plasma cells (microscopic view). (Reproduced with permission.)

The invasion of myeloma cells (cloned plasma cells) means that the normal production of plasma cells is significantly decreased resulting in an immune system that becomes compromised leading to recurrent infections. It is unrelenting in its progression and the development of drug resistance is a major obstacle in curing the disease (Dalton, 2004).

There may be a pre-existing condition called monoclonal gammopathy of undetermined significance (MGUS), which means insignificant amounts of paraproteins are present in the absence of multiple myeloma. This can transform into multiple myeloma or other associated diseases such as lymphoma or amyloidosis in approximately 26% of patients (Singer, 1997).

Myelomas are usually described in terms of secretory and non-secretory, symptomatic and non-symptomatic or smouldering. Plasma cell leukaemia is a term used when there is peripheral blood involvement accounting for >20% of cells (International Myeloma Working Group, 2003). Myelomas are also classified according to the types of Igs and the presence of light chain or heavy chain disease (for further information refer to Hoffbrand et al, 2001). Numerous bones can be diseased with myeloma cells, hence the name multiple. The common and less common clinical features of multiple myeloma are presented in *Table 1*. The cause has not been identified but certain contributory factors may be associated with myeloma (*Table 2*).

Table 1

Common and less common features of multiple myeloma

Common
Bone pain and pathological fractures
Anaemia and bone marrow failure
Infection as a result of immunodeficiency and neutropenia
Renal impairment
Less common
Acute hypercalcaemia
Symptomatic hyperviscosity
Neuropathy
Amyloidosis
Coagulopathy
Source: Singer (1997)

Multiple myeloma has an unpredictable path with numerous periods of relapse and remission. The patient can die within days or weeks of being diagnosed, but may live for many years with a 'smouldering' myeloma that does not require any medical intervention. It is difficult to anticipate how aggressive the disease is going to be. A new International Staging System, developed by the International Myeloma Working Group, has recently been published (Durie, 2006), using serum B2 microglobulin and serum albumin prognostic indicators. Previously, the most common staging system used (Durie-Salmon) was criticised as being too complex and cumbersome for clinical practice (Schey and Pallister, 2004).

Despite modern treatments of combination chemotherapy and high-dose therapies such as melphalan used in conjunction with autologous stem cell rescue (autograft transplant), multiple myeloma remains incurable with a median survival of between 3 and 4 years (Bradwell, 2003). An outline of the principles of management are given in *Table 3*. The treatment is aimed at slowing down the progress of the disease, the outcome of which may be a partial, complete or no response to therapy, controlling the symptoms and improving the patient's quality of life (Morris, 2003).

The disease and treatment can cause extreme tiredness, lethargy and depression (Smith et al, 2005). The fragility of bones means that patients with multiple myeloma are susceptible to pathological fractures and movement can be particularly painful because of the presence of bone disease. Backache, back pain and collapsed vertebral bones are common (Hoffbrand et al, 2001). *Figure 2* shows various collapsed vertebral bones and prior evidence of kyphoplasty, which is injected bone cement used to treat vertebral compression fractures.

Table 2

Contributory factors relating to the development of multiple myeloma

Genetic factors
Weakened immune system
Exposure to particular chemicals
Radiation
Viruses
Source: Morris (2003)

The NHS Cancer Plan (Department of Health, 2000) has set out to improve supportive and palliative care for adults with cancer, in collaboration with the National Institute for Health and Clinical Excellence (2004). The key topic areas include the following: communication, information, coordination of care, and psychological, social and spiritual support.

Background to the family narrative

Marian is a senior nurse and works as a clinical nurse specialist in a large teaching

hospital. Her mother Susan died of an aggressive form of multiple myeloma, which left her family completely devastated. Her parents had been married for 40 years and they had four daughters, one of whom was fostered, and a brother. During the interview Marian indicated that she would probably get upset and she did start to cry at one point.

Susan had originally gone to her GP with a history of bad headaches. Following a number of visits the GP eventually took a blood test, which showed some abnormality. This necessitated a referral to haematology and Susan underwent a period of monitoring, which lasted 2 years. Marian was vague about the abnormality detected. However, it can be assumed that a monoclonal protein had been found in the blood serum. At this stage it could have been either a smouldering myeloma (asymptomatic) or MGUS. The family was aware that Susan's condition could evolve into something more serious such as a symptomatic myeloma but did not understand the implications if it did. Unfortunately, the onslaught of the disease was aggressive and Marian describes the illness as 'hell on earth with no quality of life in between'.

Marian appears to be a strong and articulate person. She looked upon the interview as a cathartic experience and although she became really disturbed and emotional, she insisted that she wanted to carry on. Marian seemed unhappy because she had not been able to speak to her mother about death and dying.

When her mother had asked 'am I dying?' Marian had said 'no of course not'. She says that this was because no one in the family wanted to speak about Susan's death until she was actually dying and then it was not discussed with Susan. The family had wanted to stay positive. Although Marian could see that her mother was dying and was rapidly becoming a 'dying cancer patient', her coping mechanism was to push that knowledge aside and concentrate on hoping that the treatment would be successful.

Table 3

Management of multiple myeloma

Chemotherapy
High-dose melphalan with transplant
Radiation
Maintenance therapy: support therapy: erythropoietin; bisphosphonates; antibiotics; pain relief; growth factors; emergency treatment, e.g. long bone pinning, plasmapheresis, kyphoplasty
Management of drug-resistant or refractory disease
New medication used in clinical trials: thalidomide; bortezomib, PS-341 (Velcade); Doxil (long-acting doxorubicin); arsenic trioxide (Trisenox)
Further reading: Hjorth et al (1993), Riccardi et al (2000), Hoffbrand et al (2001), Silverman (2002), Cavenagh and Croucher (2004), Weber (2004), Smith (2005), Durie (2006)

Being monitored

Susan had been attending a haematology clinic for approximately 2 years. Marian was on maternity leave and was able to accompany Susan to clinic visits. The family understood that there was a blood abnormality that required monitoring. The haematologist informed them that it might not develop into anything further and, as the blood count levels remained the same, the family avoided any contemplation of what might or might not have developed.

Denial is one way that people cope with situations that are difficult to accept (Copp and Field, 2002). The following narrative reflects the denial that Susan's family adopted:

'The doctor had talked about some problems with her blood. You know I'm a nurse but I didn't really know what it was. We had this consultant who said maybe it will never ever come to anything, so we kind of lived for the moment and thought OK, lets just live with it and we even used to laugh about it. I got to go with Mum to all her clinic appointments and afterwards we'd be like laughing about this consultant because it was just our way of managing it. Mum was that type of person who would manage that. She'd just forget about it and get on with life and we'd sort of think nothing of it, and it never got worse, it was always the same.'

Feeling unwell

Following the 2-year period of monitoring Susan suddenly became unwell with general weakness and loss of appetite. Immediately before this period she had complained to Marian about her back feeling sore. As Susan had bilateral hip replacements this was not unusual. It was difficult to describe what the problem was:

'I remember spraying Ralgex on her one day and you know we had such a laugh about it because this Ralgex was so cold, and she said "Ooh yes

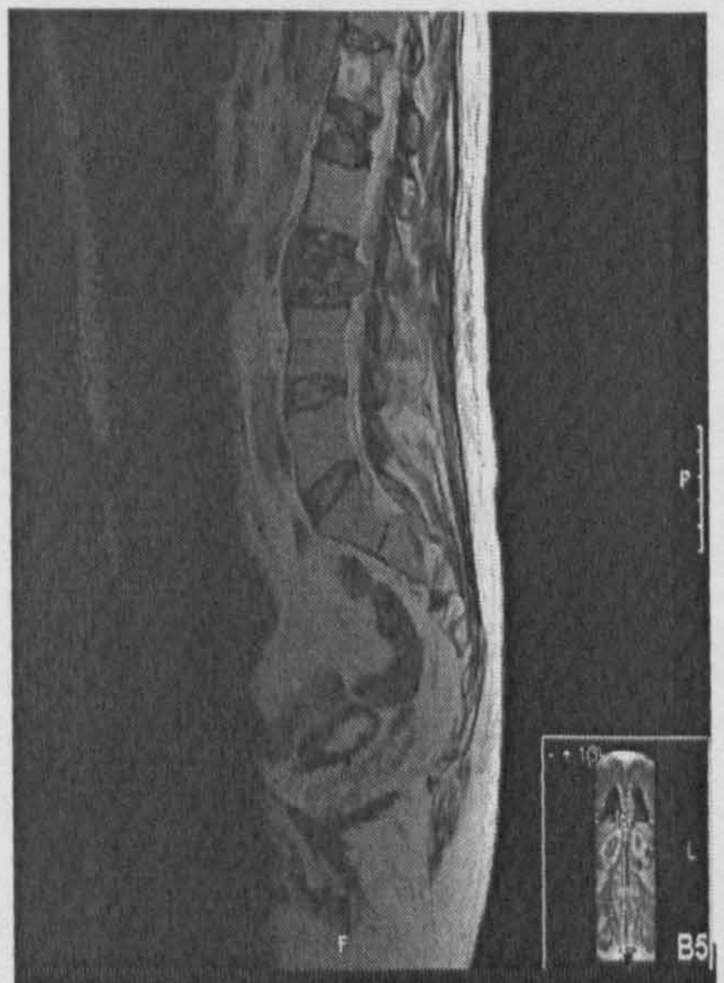


Figure 2. Magnetic resonance imaging (MRI) of whole spine showing almost complete collapse of the T9 vertebral body, partial collapse of the L1 vertebral body with evidence of prior kyphoplasty. There is partial collapse of the L3 vertebral body and a large associated soft tissue mass extending into the spinal canal. (Reproduced with permission.)

it's really helped". Quite quickly after that mum came down with an illness and was very sick. I went to see her one day and I looked at her and I said mum you look awful go back to bed. It was a morning that we were going to go to the GP and I was going with her. I said "you can't go to the GP" because mum could hardly walk. It was all very non-specific.'

Diagnosis

The GP was called and knew at a glance that Susan required immediate hospitalisation. Marian states that the GP had been her mother's doctor for a long time and knew her well. Susan was admitted to hospital in early August 2000 and was informed of the diagnosis relatively quickly. Marian describes the shock of the diagnosis and how distressing it was informing the family:

'We were in casualty and the doctor said it's your myeloma, it has flared up, that's what the problem is. Mum immediately said "I've got cancer" and she knew and you know, a diagnosis of cancer is awful for a family. I went home that day after casualty and had to tell dad, and of course he thought "that's it she's going to die" and he was very, very upset and so were all the family... that...initial shock that you've got a cancer.'

Treatment was commenced with chemotherapy to bring the cancer under control. Susan became well again fairly quickly following initial supportive treatment for hypercalcaemia and blood transfusions for anaemia. Marian states that within approximately 48 hours her mother was feeling much better after having felt 'so dreadful'. Susan was treated with chemotherapy as an outpatient and also had several hospital admissions. Initially, Susan appeared to be progressing well and was responding to treatment. Marian's younger sister was getting married. Susan's big aim was to be well enough to be able to attend her daughter's wedding:

'Mum's big aim at that time was Mary's wedding. My younger sister was getting married and that was at the end of August, so you know how quickly this happened. So at the end of August mum made that wedding and she was really well that day, really well, like her normal self and we look back on photos and think wow! But as that day progressed, by the end of the night she was sick again.'

Becoming a dying cancer patient

In October, Marian went away for a week to Ireland with her husband and baby son. It was a holiday that had been planned originally with Marian's parents but Susan was not well enough to go. Marian describes the change in her mother's appearance when she returned from Ireland. The fact that her father did not recognise the change in his wife's appearance was also noted at this time:

'Quite soon after mum had been diagnosed, it was the October and we had planned to go to Ireland all of us together with our new baby and mum and dad and of course mum's now dying, so she couldn't go and I was away for a week and came back. I went into her bedroom and just was in tears, you know. I had to leave the room in tears because there was such a drastic change, she looked so skeletal, she looked like a cancer patient, you know, quite quickly, a dying patient, and I remember being in the front room crying and dad coming in and saying "Why are you crying, she's, she's very well, she's looking"...he couldn't see any of it...'

Within several weeks Susan deteriorated and was no longer responding to the chemotherapy. A decision was taken to change the therapy:

'Mum started to deteriorate, so her bloods deteriorated, and they called us up one day to see them and they said we want to move on to another class of treatment because things are deteriorating and of course we agreed. We had to because there wasn't really another option. They wanted to do it, and I think from there on, no treatment was ever probably going to work because mum got worse and worse and then on Christmas Day I remember coming, we'd been to Dave's parents for dinner, for Christmas Day and we came and mum had had a really bad day and we called out the emergency doctor for some pain relief and she was admitted quite soon after that.'

Marian was informed that the new therapy (thalidomide) was not having any effect. Susan continued to deteriorate. It was suggested that the treatment was discontinued. Marian disclosed her feelings and stressed that, as a family, they did not acknowledge that Susan was dying. Furthermore, it was assumed that Susan was not aware of her impending death:

'A new registrar came and he'd been around for a couple of weeks and I called him at home about something and he said...your mum's figures are deteriorating, I think we should stop treatment. I can't remember what else he said but I was horrified that he would actually even go there and I just said as a family we wouldn't do that, we won't stop treatment and now I, I think was that the wrong thing to do at that time because we as a family never acknowledged mum's dying, until right at the end when mum was dying and couldn't acknowledge it herself. He said to me, this registrar, that mum would be crying at night with the nurses, so maybe she did have some knowledge of what was happening.'

The family believed and hoped for a miracle cure. They had seen an article on the internet about thalidomide and how a particular woman had been treated with success:

'I think it was probably that we as a family were never ever going to give up. We would always have that hope and that we would always try and look for this miracle I suppose. We were reading something on the website about thalidomide. You know this woman's story that it had worked. She was taking it and then wow she had made this great

recovery and I suppose I'd always thought that maybe that would happen for mum.'

Susan returned from her last hospitalisation to the family home where she had lived for more than 30 years. During that time many people came to visit. Marian recalls visitors' shock at seeing such a drastic change in her mother's appearance:

'Mum was ill but people did start to drop in and you know it was just like the shock, people knew then that she was dying. We never told anyone. You know we were so closed about what was going on but it must have been so obvious to people. She just looked like a, you know, a corpse.'

Marian talked about two distinct changes in her mother. One change was in her mother's external appearance relating to body degeneration because of the disease. The other was 'a very discrete difference in who mum was', implying there had been a subtle change in Susan's personality:

'To me she just looked awful and that's how quickly the change happened and then you know, awful bruising that came on her body. You know that's horrible at the end, yeah I suppose it wasn't a very long time span but she was just bruised everywhere. She was so thin, skin and bone and, she could hardly get out to the commode and everything was such an effort. It's just awful really. I think you know as a family we knew there was something different about her, that no one else would have seen. It was a very discrete difference in who mum was and I suppose at the time I wasn't really recognising it properly. I would just think "oh you know mum's ill" but now I think back it was the whole period, very discretely she was a bit of a changed person.'

Marian recognised that her mother had an 'underlying depression' as she had become withdrawn, distant, and tearful. Marian's thoughts were that her mother was not able to come to terms with her diagnosis. Susan was described as having been a 'funny person' who was interested in talking with people. During her illness Susan had become 'distant'. Marian suggests that this was because Susan was afraid to talk to her family about what was happening to her. In addition, the family did not want to accept that Susan was dying:

'I think she was frightened. Mum couldn't talk to us about it. I don't know why. Perhaps it's because we... just didn't want to accept that. You know mum had this very serious illness, that she was going to die with but we just always hoped she would recover.'

End-of-life care

Susan was treated with morphine for bone pain (back pain) and lorazepam was prescribed for anxiety attacks. Marian maintains that the lorazepam was very effective. It helped calm her mother, improved her wellbeing, and she appeared to be more her normal self:

'The one thing that mum was prescribed, that really did help her and I'm sure it was because, she did have a fear, was lorazepam. We used to laugh about it because they were like her little blue pills but when she'd had a lorazepam she, it really calmed, it calmed her in lots of ways and almost brought her back to being the mum that we knew because she would get a little bit panicky or withdrawn.'

The whole family was 'very pleased' that Susan was at home when she died. Susan had only been discharged from hospital a few days previously. Being at home gave the family an opportunity to participate in Susan's care and to share special moments that would never be forgotten. It also gave the family an opportunity to begin to come to terms with Susan's impending death. However, Marian claims that her father could not have coped with his wife at home for much longer. Marian sums up the period of her mother becoming 'struck down' with the illness and dying:

'Mum was diagnosed in early August and died on the 7th of February. In between, you know, it was hell on earth, mum didn't have any quality of life really because she was either in hospital or if at home, was in bed. Mum wasn't able to do anymore more than that. Sometimes she could get up and be so exhausted but the one thing, I mean, she made it to our son's christening. That was in the November. Mum had quite a good day that day, but, you know, making the christening means that she got in a car got to my house and spent quite a bit of time in bed in the spare room, but she was in quite good spirits.'

Discussion

Diagnosing people with multiple myeloma can be difficult (Watts, 2005). Back pain or backache is common and is often the first symptom that the patient experiences. However, people may have to attend the GP practice several times before the cause of the pain is investigated further. Patients may be attending the hospital for other conditions and abnormal protein or calcium levels are detected in the blood, which may alert the doctor towards the possibility of the presence of myeloma. Others may simply break a bone while carrying out household chores. These patients are seen in accident and emergency departments with a 'suspicious' pathological fracture.

The need repeatedly to visit the GP seeking help regarding a specific problem before a cancer diagnosis is made has been reported by Leydon et al (2003). These authors suggest that difficulties are encountered because of scarce resources, especially in deprived areas, additional pressure on GPs, 10-minute consultations and lack of experience and knowledge. With regard to this latter point, Leydon et al found that the patients with breast cancer were relatively satisfied with their GPs' ability to facilitate a diagnosis. This is not surprising as breast cancer can be detected quickly and easily because it is a solid tumour that is palpable and often visible to the naked eye. Other less conspicuous cancers, e.g. leukaemia or myeloma, may start out with non-specific symptoms such as mild anaemia or backache. In the

case of a symptomatic myeloma, the consequences of a delayed diagnosis will ultimately lead to delayed treatment and disease progression.

Susan's abnormal monoclonal protein levels were detected after having routine blood evaluations as a result of several visits to the GP, initially for severe headaches. The abnormal levels were not significant enough for treatment but necessitated monitoring and it was not conclusive that this condition would develop into cancer. It is known that a smouldering myeloma or MGUS can develop into a symptomatic myeloma (Singer, 1997). In Susan's case this was advantageous as it served as a prior warning and thus she was diagnosed quickly. The relationship between patient and GP is fundamental. Susan was well known to the GP. Her doctor was familiar with Susan's medical history and knew her as a person. One look was enough to inform the GP that something was very wrong and that immediate medical intervention was required.

The time of diagnosis is usually described in terms of 'a shock' for most people and their families (Thomas and Retsas, 1999; Maliski et al, 2002). Many are completely traumatised and in a state of bewilderment (Davis, 2002; Persson and Hallberg, 2004). Susan was told 'your myeloma has flared up'. She instantly knew she had cancer which implies a degree of awareness. It is assumed that the words 'myeloma' and 'cancer' had been used in a conversation between the doctor and patient at some stage. From the interview it is clear that this discussion did not take place between the patient and her family.

During the monitoring period both Marian and Susan knew that something sinister was potentially 'brewing' but chose not to acknowledge it as a way of coping with the situation. It appeared to be a case of — why worry about something that may or may not develop? Being forewarned, however, did not lessen the shock and distress associated with the diagnosis and the impact this had on the family. It can take a long time for family members to come to terms with a diagnosis of cancer (Mellon, 2002). In Mellon's (2002) study, cancer survivors and family members were so shocked at receiving the diagnosis that it was a considerable length of time after the cancer treatment had ended that they finally came to accept it.

Myelomas are often referred to as being in a state of relapse or refractory which means that the disease is not responding to treatment. Finding an effective treatment is often a challenge. It might only be achieved through persistent trial and error. The disease was particularly aggressive in Susan's case. In the terminal stages of the illness no treatment will alter the course of its progression. It is unrelenting. Hope for a miracle cure has been identified in the literature (Mok et al, 2003) and this was apparently very real for Susan's family who were influenced by other people's experience of successful treatment with thalidomide. The findings from Mok et al's (2003) study are important, despite the differences in culture and beliefs, because of the implications for nursing practice. This research explored family experience caring for terminally ill patients with cancer in Hong Kong. Hoping for a miracle, despite being told that the illness was incurable, and trying alternative herbal medicine, was described as an integral component of the process of caring.

Not all families are able to talk openly about death and dying because it is too upsetting (Greisinger et al, 1997; Copp and Field, 2002). Marian describes her mother becoming subdued and distant. This was understood as a fear of talking to her family about her situation and the possibility of dying.

Marian knew her mother was dying but was unable to discuss this with her or any other family member. This suggests that family members were protecting each other and were not necessarily in denial. Marian was under no illusion that her mother was dying. However, denial of impending death is conceptualised as an individual coping mechanism (Zimmermann, 2004).

Copp and Field (2002) discuss the open awareness culture in a hospice setting and the use of denial and acceptance of dying as alternating coping strategies used by patients at different stages of the illness trajectory. Family members were seen to be protecting one another by not talking about illness and dying. While some patients were able to discuss issues relating to their situation throughout the course of their illness, others preferred to have periods when they were not constantly reminded about their imminent death. People cope by not acknowledging that a loved one is dying. They cope with 'the now' of the situation and do not concentrate on what is about to happen because it is too painful.

Lawton's (2000) work highlights strategies employed by dying patients such as focusing on the memories of their past lives and being reluctant to discuss any topic associated with the future. Lawson provides an example of this within a day care setting. Any person showing unrealistic expectations concerning future plans was immediately excluded from the inner circle of patients attending (Lawton, 2000).

The breaking of bad news is described as 'one of the most difficult responsibilities in the practice of medicine' (VandeKieft, 2001). Bad news is defined as 'news of life-threatening illness, disability or impending or actual death' (Farrell, 1999). Doctors may withhold certain information because they have concerns about its detrimental effect on patients. Furthermore, VandeKieft (2001) argues: 'Physicians do not wish to take hope away from the patient. They may be fearful of the patient's or family's reaction to the news, or uncertain how to deal with an intense emotional response.'

Marian was the recipient of bad news when the registrar told her on the telephone that her mother's condition was deteriorating and that the health care team was considering stopping the treatment. Marian was clearly upset by this comment. The doctor could have coped with the situation more sensitively by arranging

a meeting with Marion to discuss the options in person. Effective and compassionate communication is not just a matter of discussion. Health care professionals should be prepared to provide the emotional support and respond to an individual's reactions to bad news (Dias et al, 2003).

Conclusion

The aim of this article is to describe the disease process of multiple myeloma in the context of a dying mother and the impact of the disease on the family. Susan's family had little time to come to terms with the diagnosis of cancer before Susan died. The myeloma was aggressive, unresponsive to treatment, and unrelenting. Within a short period Susan became a 'dying cancer patient'.

The narrative content provides some insight into the often unpredictable nature of the disease. The ongoing qualitative study intends to increase understanding into the impact of this debilitating bone marrow cancer, strengthen the evidence base for managing the disease and provide more supportive care, particularly at the end of life. EOLC

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Key Points

Appendix 3 Literature review (2004)

Appendix 3 Literature review 2004

SUMMARY OF QUALITATIVE STUDIES

AUTHOR AND STUDY	N	METHOD	FINDINGS
Carter, H., MacLeod, R., Brander, P & McPherson, K. (2004) Living with a terminal illness: patients' priorities.	10	Audio-taped interviews Grounded Theory analysis	Five main themes of : (1) Personal factors relating to activity level, state of mind, leisure, work, and social involvement. (2) External factors associated with environment such as health care, social services, interpersonal exchanges which helped or impeded life involvement. (3) Future issues in terms of moving on and loss of meaning regarding original plans and having to reconsider life priorities. (4) Perceptions of normality associated with re-defining present life living with a terminal illness and reflecting on the consequences of this. (5) Taking charge the central or core category viewed as the ultimate outcome from the patient's perspective in terms of maintaining control and playing an active role.
Persson, L. & Hallberg, I.R. (2004) Lived experience of survivors of leukemia or malignant lymphoma.	18	Audio-taped interviews Phenomenological-Hermeneutic approach	Three main themes of : (1) Believed in life, fought for it, and came out of the experience a stronger person. (2) Saw it as life goes on, adapted and found balance in the new life. (3) Life was over, felt out of control and lost belief in life.

SUMMARY OF QUALITATIVE STUDIES continued.

Thome, B., Dykes, A.K. Gunnars, B. & Hallberg, I.R. (2003) The experience of older people living with cancer.	41	Audio-taped interviews Latent content analysis	Four main themes of : (1) Living with cancer means bodily, mental, social, and existential experiences. (2) Being aware of the disease or not, involving either a clear or unclear view of cancer. (3) Handling daily life in terms of controlling, dis-association, adaption, and comparison with others. (4) Affirmation or rejection from the health care professionals.
Mok, E., Chan, F., Chan, V. & Yeung, E (2003) Family experience caring for terminally ill patients with cancer in Hong Kong.	24	Audio-taped interviews Grounded Theory and constant comparison analysis	Four main themes of : (1) Precondition which included subthemes of relation-al commitment, an act of showing love and responsibility, and determination. (2) Process of caregiving included subthemes of hope for a miracle, taking care, preparation for death, and adjusting to a new phase of life. (3) Consequences included subthemes of mental and physical fatique, grief and loss, peace of heart and mind, and change of world view. (4) Influential factors included subthemes of values and beliefs, and social support.

Appendix 4 Qualitative synthesis grid

Communication

	Friedrichsen & Milberg	Randall & Wearn	Byrne et al
Journal/Date	J.P.M 2006	P.M 2005	P.E & C 2002
Sample	30 doctors	15 adults	30 adults
Context	Different specialists	Leukaemia and Lymphoma	Different cancers
Data collection	Interviews	Interviews	Interviews
Setting	Hospitals Sweden	Haematology Clinic UK	Oncology clinics- and day unit UK
Analytical approach	Phenomenography	Thematic analysis	Thematic analysis
Categories of respondents	Doctors giving bad news to patients	Patients with blood cancers	Patients with various types of cancer
Synthesis categories	Communication Bad news	Communication Bad news	Communication Response
Subcategories (concepts)	Incurable cancers Breaking news Losing control Demanding task Maintaining control Choice of words Concentration Perceptions Existential thoughts No-one wants to hear The healer The executioner Feelings of guilt Disappointment Harming patients Expectations Life and death Making judgements Relationships Showing emotions Bad starting points Competence Time constraints Interruptions Misinterpretations Cultural differences	Personal qualities Expertise Rare cancer Friendly Spending time Sympathetic Honesty Hope Fight Simple talk Metaphors Atmosphere Different approaches Unrushed Rushed Right to choose Leaflets Control Written summary Medical terms Confusion Being monitored Kept informed Emotional turmoil Continuity Support	Hidden disclosure Hidden tensions Concealing distress Rejecting cancer Effort and struggle Being normal Minimising disease Accepting cancer Shock Bewilderment Finding cause Fear Inevitability Assimilating illness Life re-evaluation Burden Brave face Impact on others Clinical collusion Family collusion Fighting Suppression Mixed emotions Staying positive Confusion Protecting others

Communication			
Journal/Date	Friedrichsen et al P.M 2002	Bakker et al P.E & C 2001	Barnes et al WJM 2000
Sample	30 adults	40 females	32 females
Context	Different cancers	Breast cancer	Breast cancer
Data collection	Interviews	Interviews	Interviews
Setting	Palliative unit Sweden	Oncology clinics Canada	Breast cancer- Centers UK
Analytical approach	Phenomenography	Thematic analysis	Content analysis
Categories of respondents	Patients with incurable-cancers	Patients with breast cancer	Mothers of school-age children
Synthesis categories	Communication Language	Communication Interactions	Communication Talking to children
Subcategories (concepts)	Verbal expressions Ending treatment Interpretation Understanding Choice of words Indirect warning words Forewarning words Evasive words Vague sentences Ambiguous words Threatening words Fortifying words Supporting words Maintaining interest Reassurance Positive message Underlying message Decision making No-chemo-no-side effects Metaphors Time focus Ultimate message Separation focus Death focus Abandoning words Negative feeling	Information Routine check ups Doctor mode Medically focused "Doctor talk" p 64 Physical exam' Lab' results Treatment Nurse mode Problem solving Being listened to Individual needs Main support Power and control Fighting the cancer Partnership Decision making Continued support Sustaining hope Having confidence Gaining knowledge Relationships Role expectations Self help Assertiveness Connectedness	Timing of disclosure Time of discovery Time of GP visit Time of appointment Time of diagnosis Time of surgery Decision making Withholding Avoidance Facing questions Preventing distress Protection Understanding Special occasions Right to know Child's trust Family discussion The cancer word Appropriate language Needing guidance Being honest Child's awareness Child's coping Feeling reassured Family counselling Preparation

Impact on life

	Houldin	Johansson et al	Denny
Journal/Date	**ONF 2007**	**C.N 2006**	**J.A.N 2004**
Sample	**14 Caregivers**	**5 adults**	**15 females**
Context	**Advanced colo-rectal cancer**	**Incurable cancers End of life**	**Endometriosis**
Data collection	**Interviews**	**Focus group meetings**	**Interviews**
Setting	**Cancer Centre USA**	**County Hospital Sweden**	**Gynaecological-Dept' UK hospital**
Analytical approach	**Content and constant comparative analysis**	**Content analysis**	**Thematic analysis**
Categories of respondents	**Spouses and friends as caregivers**	**Living with incurable cancer**	**Living with-incurable disease**
Synthesis categories	**Quality of life Disrupted life**	**Quality of life Patients' perceptions**	**Quality of life Delay in diagnosis**
Subcategories (concepts)	**Total disruption** **Changing priorities** **Responsibilities** **Struggle** **Unable to plan** **Change in routine** **Impact on work** **Social impact** **Life insurance** **Chemotherapy** **Sperm bank** **Cancer diagnosis** **Helplessness** **Relationships** **Financial concerns** **Medical knowledge** **"We are at war" p326** **Unable to talk** **Staying positive** **Normal as possible** **Being parents** **Cancer word** **Talking to children**	**Palliative homecare** **Ordinariness** **Normal things** **Able to function** **Alleviate suffering** **Physical well being** **Mental well being** **Living their lives** **Personal strategies** **Managing pain** **Positive life** **Memories** **Feeling needed** **Not just an ill person** **Motivation** **Maintaining interest** **Significant relations** **Essential networks** **Communication resonance** **Emotional support** **Positive talks** **Nurse contact** **Contact continuity**	**Being taken seriously** **Intense pain** **Dyspareunia** **Sexual relationships** **Treatment** **Side effects** **Ineffective treatment** **Operations** **Social relationships** **Employment** **Partners support** **Supportive employer** **Fear of recurrence**

Impact on life

Journal/Date	**Howell et al C.N 2003**	**Elmberger et al C.N 2002**	**Molassiotis & Morris C.N 1998**
Sample	**18 females**	**8 males**	**28 BMT adults**
Context	**Recurrent ovarian-cancer**	**Haematological malignancies**	**Acute myeloid-leukaemia**
Data collection	**Telephone-interviews**	**Interviews**	**Written narrative**
Setting	**Cancer Centre Canada**	**Transplant and OPD Sweden**	**BMT Centre UK hospital**
Analytical approach	**Thematic analysis**	**Interpretative description**	**Content analysis**
Categories of respondents	**Living with-recurrent cancer**	**Fathers living with cancer**	**Survivors**
Synthesis categories	**Quality of life Waiting for recurrence**	**Quality of life Impact on family**	**Quality of life pre and post transplantation**
Subcategories (concepts)	**Fear Ups and downs Ongoing treatment Side effects Tumour markers Watchful waiting Devastation Hopelessness Changed attitudes Communication Struggle Becoming assertive Taking control Options Being monitored Progressive disease Drug resistance Gaining knowledge Demanding treatment Making decisions Prolonging life**	**Transition Changed image Changed role Burdensome More time at home Daily treatment Not taken seriously Family perceptions Misunderstandings Isolation More family time Childrens' reactions Gaining control Using metaphors Gaining knowledge The internet Hidden disclosure "Going to fight it" p481 Balance emotions Fear of relapse Hidden tensions Protecting children Sharing knowledge Value of family life Family support Struggle**	**Normality Fulfillment Independence Being able Being supported Fatigue Loss of work Restrictions Family problems Re-evaluation No difference Coping with family Returning to work Disabled Fears of recurrence Infertility Socialising Future plans Finance**

Supportive care needs

	Bottie et al	Clarke et al	Ziebland et al
Journal/Date	C.N 2006	C.N 2006	P.E & C 2006
Sample	15 nurses	16 adults	43 females
Context	Haematological-oncology	Melanoma and-Breast cancer	Ovarian cancer
Data collection	Focus groups	Interviews	Interviews
Setting	Haematology cancer-ward. Australia	Cancer Centre UK Hospital	DIPEx.org UK
Analytical approach	Thematic analysis	Thematic analysis	Thematic and constant comparative analysis
Categories of respondents	Experienced nurses working in cancer ward.	Cancer patients	Participants from the DIPEx project
Synthesis categories	Psychosocial support Barriers	Psychosocial support Gender differences	Psychosocial support Treatment decisions
Subcategories (concepts)	Workload Time to talk Inexperienced Lack of knowledge Good time to talk Building relationships Gaining trust Working part-time "Band-Aid fill-in" p312. Continuity of care Struggle Competence Understanding Complex medical history Primary nurse Emotional labour Personal boundaries Providing support Key times Difficult times Communication Approach to bad news Feeling uncomfortable Feeling isolated	Formal system Informal system Support networks Different needs Access Less common cancers Emotional support Gender Busy clinics Consultations Time pressure Breast care nurse Wives' support Support for wives Perceptions Specialist nurses Coping "Internal struggle" p71 Men's support needs Women's support needs Support for partners Burden of support	Feeling overwhelmed Treatment choices Unable to cope Out of control The modern patient Right to choose Right choice Wrong choice The responsibility Medical uncertainty "Went along with" p363 Doctor's choice Doctor's expertise Unable to choose Asking questions Second opinion No 'real' choice Recommendations Searching the internet Time to research Becoming familiar Able to discuss More active role Burdensome choice Contradictory advice Struggle

Supportive care needs

	Furness B.J.N 2005	Chapple et al B.J of G.P 2004	Murray et al BMJ 2002
Journal/Date			
Sample	38 adults	45 adults	40 adults
Context	Facial surgery	Lung cancer	Lung cancer- Cardiac failure
Data collection	Focus groups and interviews	Interviews	Interviews and Focus groups
Setting	Surgical unit UK Hospital	At home UK	Community Scotland
Analytical approach	Grounded theory	Thematic analysis	Thematic analysis
Categories of respondents	Patients and significant others	Living with lung cancer	Patients, carers and professionals
Synthesis categories	Psychosocial support Categories of support	Psychosocial support Financial benefits	Psychosocial support Prioritisation
Subcategories (concepts)	Informational support Practical help Material help Emotional support Psychological support Shock Unprepared Time to talk Seeing my face Unexpected emotions Needing support Support groups Specialist nurses Physical changes Prostheses Reconstruction Loss of teeth Assertiveness Accessing help Unable to speak Family support Emotional adjustment Staff awareness Availability and need Staff approachability Long-term follow-up	Accessibility Stigmatisation Barriers to obtain Reluctance to seek help Justification Feeling ashamed Being a man The provider Having cancer Wanting to be normal Barriers due to illness No backdated benefit The benefits system Uninformed Barriers due to failure Bureaucratic barriers Complicated forms Misinformed Macmillan nurse Welfare rights officer Fight and tussle Being acknowledged Struggle Better access Immediate access Macmillan grant	Accessibility Different trajectories Written information Sound understanding Poor understanding Protecting patients Hidden disclosure Decision making "Time bomb" p3 Persistent threat Struggle Side effects Feeling useless Social isolation Comorbidity Increased disability "Knacker's yard" p3 Uncertainty Support service barriers Needing support Clinical nurse specialists Hospital car parking Palliative care services voluntary agencies Service provision Misunderstanding of roles

Appendix 5 Synthesis interpretations

SECOND-ORDER NTERPRETATION

(a) *Breaking bad news involves a risk of losing control* and required all the doctor's concentration and effort. Not knowing how the patient will respond created some anxiety for the doctors who were afraid of exposing their personal feelings.

(b) *Perceptions relating to existential thoughts* included: role change from healer to executioner. Feeling guilty, alone, and inadequate feeling that enough had not been achieved. Feeling disappointed, that harm was being caused to the patient. Not living up to expectations. Forced to make moral judgements about life and death.

(c) *Perceptions relating to relationships*: risk of losing objectivity and becoming emotional. Strained relationships with patient and family members. Uncertainty about translations. No previous relationship and bad starting points.

(d) *Perceptions relating to knowledge*:
Science was not always reliable. Impossible to be updated about everything. Difficulty of transferring evidence-based medicine to the suffering person. Medical competence questioned. Unable to answer existential questions. Challenges of delivery.

(e) *Perceptions relating to time and environmental disturbances*:
Lack of time. Difficult to concentrate due to interruptions.

THIRD ORDER INTERPRETATION

Maintaining control is more likely when the doctor is well prepared experienced, competent, left undisturbed and knowledgeable about the patient when disclosing bad news.

The concept of breaking bad news from the doctor's perspective.

Appendix 5.

SECOND-ORDER INTERPRETATION

(a) Personal qualities and expertise were considered vitally important. Patients needed to have confidence and trust their doctors when receiving bad news.

(b) The amount of time available to the patient was a major factor that contributed to a more successful encounter. There was a strong preference for seeing doctors who were prepared to spend the time with the individual.

(c) Providing information, having all questions answered and being in control of the amount of detail that could be accessed at the convenience of the individual (written information) also enabled choice to do so.

(d) Unable to ask questions at the time of diagnosis through lack of knowledge and becoming confused when complicated medical terms or abbreviations were used.

(e) The ongoing process following bad news highlighted the importance of continuity and dealing with the same doctor throughout. Being followed up regularly and kept informed was crucial.

(f) Emotional support at the time of receiving bad news and during illness was usually provided by partners, close friends or family members who accompanied patients. These individuals also acted as advocates and kept other family members informed and updated.

THIRD ORDER INTERPRETATION

Healthcare professionals were perceived as having specific personal and professional characteristics that increased their chances of establishing a rapport with patients and their families.

Feeling rushed, seeing a new doctor, hearing bad news and the use of complex medical terms or unfamiliar abbreviations were more likely to increase confusion and distress levels.

SECOND-ORDER INTERPRETATION

(a) Concealing distress or hidden tensions was one way of coping with the situation and protecting other close family members or friends. Putting on a 'brave face' was a common strategy used to suppress emotional feelings and avoid distressing others.

(b) Effort, struggle and fight were defined as common responses used to minimise or reject the cancer. The resistance was generally aimed at the emotional reactions to the illness and effort to restrain them.

(c) An emphasis on staying positive meant that individuals were not expected to exhibit negative characteristics or discuss concerns that may not have been viewed as positive. It is suggested that emotional expression was discouraged by the professionals.

(d) Wanting to maintain normality, familiar routines and not wanting anything to change were another response that focused on minimisation of the cancer.

(e) Minimising the seriousness of the illness was characterised by individuals through statements that reflected this such as comparing themselves to others that they perceived as being in a worse situation than themselves.

(f) Responses relating to acceptance of cancer was viewed in terms of having been through or existing through a period of time when individuals were in a state of shock, confusion, disorientation and bewilderment.

THIRD ORDER INTERPRETATION

Encouragement to stay positive and 'fight' the cancer was interpreted by the patients as 'fighting' their emotional responses to the disease. This had an adverse effect on participants who felt that it was not acceptable to show any emotion and consequently they were forced to suppress their feelings.

The concept of response to cancer.

(g) Fear of recurrence of cancer and fear of how individuals would cope in these circumstances was defined in terms of a "constant struggle with the fear" (Byrne et al 2002:19).

(h) Accepting the reality of the situation was perceived in terms of nothing could change the fact that the cancer existed therefore the illness trajectory, surgery or treatment were inevitable.

(i) Re-evaluation of life and putting things into perspective meant that being diagnosed with cancer had a profound effect on the way individual's priorities and lives changed.

The concept of response to cancer.

SECOND-ORDER INTERPRETATION

(a) Doctors' use of language and choice of words had a monumental impact on how patients interpreted the information given.

(b) *Indirect warning words* included language suggesting that communication was vague but forewarning leaving the individual to make sense of what was being disclosed.

(c) *Forewarning words* such as 'unfortunately' stated at the beginning of the sentence or a pre-warning statement such as 'I am afraid there is no good news' are perceived as rapid psychological preparation.

(d) *Evasive words* were sometimes used at the time of transfer to palliative care to avoid the reason underpinning the move or when discussing prognosis and acknowledging a realistic amount of survival time an individual may have.

(e) *Emotionally trying words* related to patient experiences involving feeling threatened or abandoned associated with the ending of treatment and the prospect of waiting to die.

(f) *Threatening words* were generally associated with explanations concerning progression of disease and that it would have to run its course meaning cancer treatment was not viable or was no longer going to have any impact.

THIRD ORDER INTERPRETATION

Avoiding the use of threatening, abandoning or ambiguous language and using forewarnings and fortifying words can achieve delivering a message that encompasses bad news more effectively.

The concept of language when ending cancer treatment.

(g) *Abandoning words* suggested that no more could be done for the patient regarding active cancer treatment and despite being informed of palliative symptom control and supportive care they continued to feel abandoned.

(h) *Fortifying and supportive words* produced a positive message signifying reassurance and support regardless of how difficult the situation had become.

(i) Specific messages focused on discontinuation of treatment, improving quality of life, implicit or explicit threat of imminent death and estimated survival time, which was perceived as extremely frightening.

(j) Ultimatums were sometimes offered to individuals as incentives in order to continue with cancer treatment, which was perceived as threatening because the patient may not be able to meet the demands from the healthcare professional.

(k) The handing over of responsibility for care from the cancer specialist to the palliative hospital-based home team was experienced by the patients in terms of being divorced from the specialist doctors and hospital departments normally attended.

The concept of language when ending cancer treatment.

(l) The specific message that focused on death and the process of dying was described as gloomy, no hope, intensive and frightening resulting in fear and depression. The patient understood this message to mean that they would die very soon.

©

The concept of language when ending cancer treatment.

SECOND-ORDER INTERPRETATION

(a) One mode of interaction centred on routine clinic visits involving mainly "doctor talk" with a focus on the disease and treatment (Bakker et al 2001:64). The encounter was typically structured around a succession of questioning initiated by the doctor and physical examination.

(b) Interaction with nurses during chemotherapy treatment was often initiated by patients who felt at liberty to ask asked questions and had telephone contact with the oncology nurse. The focus of these encounters was typically on how the individual was coping and was not therefore entirely centred on the disease.

(c) Healthcare professionals were perceived as having power and control associated with their knowledge and expertise. Patients expected them to share information and therefore transfer some of the power and control enabling them to interact more effectively.

(d) Patients suggested that bad news should be given in an honest but positive way and specifically needed firm reassurance that they would receive continued support from the healthcare professionals.

(e) The role and responsibility of the doctor (oncologist) was perceived as the major healthcare professional providing all the relevant medical information and to validate knowledge acquired from external sources such as the Internet.

THIRD ORDER INTERPRETATION

Participants receiving chemotherapy as outpatients expected to take on more responsibility for their own health needs. Patients anticipated that healthcare professionals would be prepared to share their knowledge and expertise, which was perceived in terms of having power and control.

The concept of interactions between patients and healthcare professionals.

(f) The role and responsibility of the nurse was perceived as supportive advocates and interpreters reiterating and explaining what had transpired during consultations.

(g) It is suggested that all participants believed they had a responsibility to take on board an active role when communicating with healthcare professionals and if necessary become more assertive.

(h) *Connectedness* defined as "conscious effort for both parties (patients and professionals) to work as partners" p66, required trust, partnership, and validation of patients' feelings, emotions and beliefs for a successful and connected relationship to be established.

The concept of interactions between patients and healthcare professionals.

SECOND-ORDER INTERPRETATION

(a) Decisions to disclose information to children concerning illness were often determined at a specific time such as following confirmation of diagnosis or when surgery had been arranged.

(b) The use of the word cancer was avoided because cancer was associated with death and dying. Children would therefore not make assumptions or ask questions about death and dying.

(c) The decision to withhold information concerning illness from children was based on the desire to protect them from anxiety and upsetting news.

(d) The decision to withhold information concerning illness from children may be due to parent's underestimation of their children's knowledge and understanding.

(e) The decision to withhold information concerning illness from children may be determined because of a specific event, special occasion or time of year such as a birthday or Christmas.

(f) Mothers who communicated in detail about cancer with their children argued that the child had a right to the information. Being honest with the child maintained trust and facilitated family discussion.

THIRD ORDER INTERPRETATION

Parents are sometimes uncertain about how, when and if they should tell their children about cancer (or serious illness) and the potential implications. Professional guidance, family counselling, or the appropriate healthcare professional can help parents communicate more effectively with their children and tailor the information to their level of understanding.

The concept of talking to children about cancer.

(g) Parents who believed that communicating with their children was important did so for the following reasons: the need to talk about the illness as a family; the children would find out about the illness sooner or later; it prepared the children for the future.

(h) Parents believed that they would lose their child's trust and that children may become resentful when parents are not open and honest about their illness and what is happening to them.

(i) Parents believed that children were aware of their surroundings and sensitive to sudden change in behaviour. Explaining to children about the illness would therefore alleviate children's anxiety

(j) Parents suggested a need for information about how to approach their children and the most appropriate language to use and professional guidance on how to prepare their children for the experience of illness and effects of chemotherapy.

The concept of talking to children about cancer.

SECOND-ORDER INTERPRETATION

(a) Family members/partners caring for their loved ones with cancer experienced total disruption in their lives because of the illness, increased responsibilities and inability to plan.

(b) Individuals struggled to maintain a balance between the disruption caused by the illness and a semblance of normality in family life.

(c) Disruption impacted on all aspects of life including work, relationships, future plans, family routines, changed priorities, additional responsibilities and struggling to achieve a balance.

(d) Taking care of a loved one with cancer was associated with learning and gaining expertise about the disease, its implications and understand more about the care giving, how to manage and to communicate more effectively with healthcare professionals.

(e) Higher distress levels were reported in younger families with children and at the peak of their careers.

(d) Staying positive, maintaining faith, being realistic, talking about the illness and getting as much support from friends were strategies employed to enable families to cope with the disruption.

(e) Maintaining a normal family life and normal routines was a monumental concern especially relating to how to approach the children and other family members with handling of disclosure.

THIRD ORDER INTERPRETAION

Remaining in a positive frame of mind, being open and realistic, receiving support from family or friends, and maintaining some semblance of normality helped participants who struggled with stress and disruption in their lives while caring for their loved ones.

The concept of disrupted life.

SECOND-ORDER INTERPRETATION

(a) Individuals living with incurable cancer and receiving palliative care at home valued the ordinary things in every day life and being able to undertake physical activities.

(b) Relief from pain and fatigue meant that participants had the physical strength to undertake activities and were able to function independently.

(c) Physical well being meant being uninhibited and liberated from symptoms such as pain, breathlessness, fatigue and to be able to eat and sleep normally.

(d) Psychological well-being included being free from pain and other emotional states such as depression and anxiety.

(e) Personal diversion tactics such as keeping occupied were employed with the aim of distracting the presence of pain.

(f) Focusing on happy and meaningful memories was significantly inspiring and helped to maintain a positive life.

(g) Being needed was particularly important because this was understood as, that they (participants) were perceived as the people that they were before their illness and others felt they could seek advice from.

(h) Essential social networks encompassing family, friends, healthcare professionals, chaplains, work colleagues and pets

THIRD LEVEL INTERPRETATION

Participants' priorities associated with their quality of life while living with terminal cancer was being able to function independently and being treated as the person they were before they had the illness.

(affectionate cats or dogs) all contributed towards providing comfort, emotional support and gave life a positive meaning.

(i) Resonance in communication developed with family and healthcare professionals, which was fundamental. Having someone at home to talk with was viewed as particularly important.

(j) Managing and being in charge when ill was interpreted as taking control of difficult situations through sheer obstinacy and determination not to give in.

(k) Reflecting on the important things in life, living life to the fullest potential, making the most of every day and concentrating on positive thoughts facilitated their (participants) coping.

The concept of quality of life.

SECOND-ORDER INTERPRETATION

(a) There was a significant period of time (months to several years) between the onset of symptoms and diagnosis and recognition of the disease despite being seen by GPs.

(b) Normalisation of symptoms suggest that doctors make assumptions in favour of normal physiological processes and are not always prepared to consider alternative causes associated with disease.

(c) Women were able to make the distinction of pain associated with the disease through its intensity and duration in comparison to pain or discomfort associated with normal menstruation.

(d) Pain during and following sexual intercourse (dyspareunia) a common symptom of the disease was not generally discussed during consultations by the gynaecologists or the women (participants) who considered the subject was too personal to disclose.

(e) The impact of this disease had a profound effect on sexual relationships and the potential for destroying and ending a personal partnership or marriage.

(f) Undergoing repeated surgical procedures to treat the disease tended to be more preferable than medical intervention because of the unpleasant side effects from the medication, which only offered temporary relief.

THIRD LEVEL INTERPRETATION

Delay in diagnosis often occurred because healthcare professionals perceived that participants' symptoms were insignificant or associated with normal physiological processes (period pains) regardless of the severity of the pain experienced.

Some participants continued to have their illness trivialised or not taken seriously within their workplace and consequently felt unsupported by their employers and work colleagues.

The concept of delay in diagnosis.

(g) Lack of understanding in the work place by colleagues or management staff resulted when the participant's illness was trivialised or not taken seriously.

(h) Recurrence of symptoms was a monumental concern and worrying about how they (participants) would cope in the event.

The concept of delay in diagnosis.

SECOND-ORDER INTERPRETATION

(a) Individuals may or may not want to take on board statistics or specific information relating to their survival particularly at the time of their diagnosis or when treatment is being discussed.

(b) Being forewarned about recurrence did not always prepare individuals for it. Participants experienced shock and devastation when informed of recurrence of the cancer although it had been anticipated.

(c) The waiting and attending follow up clinics during monitoring was perceived as frightening or living in fear.

(d) Shorter remission times following diagnosis and treatment was perceived as unrelenting and continuous with ongoing treatment.

(e) Self monitoring and keeping a watchful eye on disease markers made the participants aware of potential indications when the cancer was recurring, A slight elevation therefore was threatening and frightening

(f) Participants felt that their situation was helpless and hopeless when the cancer recurred. It was also perceived that the attitudes of healthcare professionals had changed at this stage exacerbating the feeling of hopelessness.

THIRD ORDER INTERPRETATION

Forewarning participants that their cancer was likely to recur did not always prepare them for the shock and devastation associated with the second and subsequent recurrences or progression of their disease.

The concept of waiting for recurrence.

(g) It was generally perceived that information regarding treatment options from healthcare professionals was less forthcoming once recurrence had come about.

(h) Conflict arose between the doctors 'wait and watch' policy and participants struggling to access treatment during recurrence of cancer.

(i) Dealing with treatment again meant having to deal with the progression of the disease combined with serious adverse events such as extreme fatigue or menopausal symptoms associated with surgery (hysterectomy) or chemotherapy.

(j) Becoming assertive and more involved in decisions regarding treatment options became more apparent when participants had gained experience and knowledge associated with their disease and how they reacted to previous treatment.

(k) An attempt to regain control was synonymous with gaining special knowledge relating to various alternative therapies available that some women took on a 'trial and error' basis.

The concept of waiting for recurrence.

SECOND-ORDER INTERPRETATION

(a) Illness caused transition in self-image from a strong athletic and healthy man to a sick and feeble man; transition also extended to a man's self-image as a father or as a motivated and energetic working person earning a regular income.

(b) A changed father's role was defined as spending more quality time with the children at home and developing a closer bond.

(c) Men sometimes felt isolated and believed that their families did not take the illness seriously.

(d) Men were aware of their children's reactions to dramatic change such as hair loss. Otherwise the children were perceived as normally unperturbed by the illness and more interested in other things.

(e) Attempts to regain control and restore self-image were determined through planning and setting goals.

(f) Balancing emotions was discussed in terms of managing through suppression of negative feelings in the presence of others (hidden tensions).

(g) Some of the fathers who spoke to their children about the illness omitted to use the word cancer with the intention of protecting them from distress (cancer was associated with death and dying).

(h) Some of the children were affected by the illness and were very anxious about their father potentially dying.

THIRD ORDER INTERPRETATION

Participants' perceptions of themselves as working men and fathers before the illness were totally transformed as a result of the illness and spending more time at home with their children.

The concept of impact on family.

(i) The men re-evaluated their lives because of the illness, which meant a change in priorities and appreciation of more interaction with the family and enjoying life more.

The concept of impact on family.

SECOND-ORDER INTERPRETATION

(a) Quality of life was perceived by participants as living life in a normal way and being able to do everything they did prior to the illness.

(b) Quality of life meant enjoyment, fulfilment and appreciation for life and to be able to function to the best of their ability despite fatigue and restricted energy levels.

(c) Being healthy, fit and able in the absence of physical and emotional sequelae.

(d) Having independence and not having to rely on others for assistance or feeling restricted.

(e) To maintain normal relationships with family, friends and working colleagues. To be able to take care of the family and be there to see the children mature into adults.

(f) To be able to continue with a working life or career and fulfil ambitions. To be able to maintain social activities and have a normal social life.

(g) Quality of life relates to feelings of happiness, harmony and being content, a safe environment and good nutrition.

(h) The negative impact of the transplant was increased fatigue and general weakness, decreased energy levels, loss of employment,

THIRD ORDER INTERPRETATION

Quality of life following bone marrow transplantation was perceived by many participants in terms of fatigue, loss of employment, restrictions in physical activities, coping with ongoing physical symptoms, worrying about recurrence of disease and the need for ongoing support.

The concept of life following transplant.

coping with family life, restrictions in daily activities because of disability, and fear of recurrence.

(i) The positive aspects of life following transplant were re-evaluation and increased appreciation for life and time to learn or aim for appropriate or achievable leisure pursuits.

(j) Concerns relating to the future focused on quality of life and health status, fear of the cancer returning, ongoing side effects from treatment, making plans and worrying about finances.

The concept of life following transplant.

SECOND-ORDER INTERPRETATION

(a) From a nursing perspective finding the appropriate time to talk was usually during nursing activities such as assisting patients with their hygiene. This enabled the patient to initiate the conversation in informal and non-threatening surroundings.

(b) Barriers to providing psychosocial support were workload, lack of competence or experience, and the actual time that the patient needed to talk did not always correspond with the time a nurse was available to listen.

(c) Working as a primary nurse provided continuity of care and a trustful relationship with the patient facilitating more opportunity to meet the patient's individual needs.

(d) Nurses involved with patients' distressful or upsetting episodes utilised their own personal distancing strategies aiming to look after or protect themselves from emotional instability.

(e) Nurses identified key points in time along the illness trajectory when their patients (with haematological cancers) required more psychosocial support and times when they required less.

(f) Key points in time along the illness trajectory were identified as: transferring from aggressive treatment to palliative care; the advanced stages of the disease (end-of-life); uncertain intervening periods; and prolonged hospitalisation.

THIRD ORDER INTERPRETATION

In order to improve or enhance the provision of psychosocial support for patients with cancer, participants (nurses) recognised that the time had to be right for the patient's hour of need. In addition to the time element, competence, experience and the ability to demonstrate knowledge of understanding about the patient's complex medical history represented the key criteria to building a trusting relationship and eliciting the patient's psychosocial support needs.

The concept of barriers in support services.

(g) Nurses postulated that communication and collaboration between themselves and their colleagues as a multidisciplinary team was inadequate.

The concept of barriers in support services.

SECOND-ORDER INTERPRETATION

(a) Female patients were more likely to seek help with their emotional needs and felt less satisfied with the available support than male patients.

(b) Women were more likely to observe that clinics were busy and were reluctant to take up too much of the consultant's time because of this.

(c) For female patients with breast cancer access to support was facilitated through the availability of specialist breast care nurses. Specialist support services were not available for patients with melanoma.

(d) Male patients were less likely than females to seek help with their emotional needs but were aware that there was help available.

(e) Men were more likely to discuss emotional issues with their wives who were perceived as their main emotional support. Healthcare professionals were perceived as information providers.

(f) Male patients acknowledged that their wives might have benefited from emotional support.

(g) Men's perceptions of emotional support were different to women's. For example men perceived the usual verbal exchange and interactions with the healthcare professionals as emotional support.

THIRD ORDER INTERPRETATION

Male patients were less likely to seek professional help for their emotional support when compared to female patients. Male patients understanding of emotional support was different to female patients and therefore their needs were not clear.

Male patients tended to discuss emotional issues with their wives, which may have become an additional burden impacting on their wives' anxiety levels. Men perceived that their wives might have benefited from emotional support implying their wives had unmet emotional needs.

The concept of gender differences.

SECOND-ORDER INTERPRETATION

(a) Women usually became more involved with decision making in relation to treatment choices when they had become more knowledgeable about their illness; and gained experience of how their bodies reacted to some of the medication or chemotherapy agents.

(b) Women often 'went along' with the doctor's recommendations because at the time of diagnosis, they were too shocked or incapacitated. After diagnosis they may not have experienced sufficient time to gain the knowledge required to participate in decision-making regarding treatment options.

(c) Some women were more proactive and sought advice or a second opinion. They were more questioning but complied with the doctor's recommendations for treatment and felt that they were not offered any choices.

(d) Women who refused treatment or stated that they had experienced a bad reaction to an agent were offered an alternative choice.

(e) Choices of treatments offered were sometimes perceived as burdensome. Participants were unable to comprehend why they were presented with choices while in a "traumatised state" (Ziebland et al 2006:364).

THIRD ORDER INTERPRETATION

Participants were more likely to be able to engage in discussions regarding their illness and treatment options when they had gained experience and knowledge that would enable them to do so.

Participants expected healthcare professions to provide all the available choices but to be aware that they may not be able to make a decision or they may not want to make a decision.

The concept of making choices.

(f) Choices were sometimes influenced by the availability of an expensive agent that people had campaigned for. Consequently participants may have felt obliged to have this specific agent when offered.

(g) Doctors may be influenced by litigation cases and reluctant to give an opinion when presenting treatment options regarding surgery and chemotherapy.

The concept of making choices.

SECOND-ORDER INTERPRETATION

(a) Strengths in the *informational* support category comprised of detailed preoperative information given to reduce anxieties however it also highlighted potential worst case scenarios and increased the level of distress.

(b) Deficits in post-operative information occurred when surgery had been more extensive than anticipated and surgeons neglected to discuss this. Information relating to physiological and psychological aftermath of surgery and support services in the community were inconsistent.

(c) Information needed to include friends and relatives so they were in a position to understand what was happening and provide continued support to their loved one.

(d) The *practical help* support category identified specific needs such as needing prostheses and new teeth following facial surgery. Families struggled accessing some of these services.

(e) The *emotional* support category identified individuals whose specific needs were not being met. Having someone to talk with at the hospital was often determined through how approachable staff appeared and if they had a warm and caring personality.

(f) Participants suggested that many of the healthcare professionals lacked the specific skills and expertise required to meet their emotional demands or provide appropriate ongoing psychological support.

THIRD ORDER INTERPRETATION

Preoperative *Informational* support provided by the healthcare professionals took precedence over post-operative information concerning the physiological and emotional aftermath of facial surgery and ongoing psychosocial supportive care needs.

The concept of support categories.

(g) Participants suggested that healthcare professionals seemed oblivious to the impact disfigurement had emotionally and socially on their psychological well-being, self-confidence and self-esteem.

(h) Specific points in time were identified when participants needed emotional support, following surgery and following discharge over a prolonged period of time.

(i) Hospital staff were perceived as being too busy to provide emotional support.

The concept of support categories.

SECOND-ORDER INTERPRETATION

(a) Patients did not always claim for their financial benefits because of the associated stigma attached.

(b) Stigma associated with having cancer sometimes prevented participants from seeking financial assistance.

(c) Patients with lung cancer who were unable to claim for disability living allowance straight away (at time of diagnosis) were unable to claim for any backdated entitlement.

(d) Specialist advice was required in relation to completing the appropriate application forms when applying for benefits, as the process was complicated and confusing.

(e) Participants relied on healthcare professionals to support them in relation to accessing benefits. Participants were not always aware of their entitlements to benefits and support from professionals was described as "dismal" (Chapple et al 2004:591).

(f) Claim forms were lengthy and complicated. Participants were not clear about which benefits they were eligible for in their circumstances.

(g) Participants struggled to cope with financial difficulties and feeling very ill while dealing with the slow bureaucratic process of claiming benefits, which often took several months.

THIRD ORDER INTERPRETATION

Enhanced access and claiming benefits early was made possible when a healthcare professional took the initiative rather than waiting for participants to ask or assuming that someone else will have dealt with the matter.

The concept of financial support.

SECOND-ORDER INTERPRETATION

(a) Patients with lung cancer often had a vague onset of symptoms and perceived that the diagnosis was delayed. They had a distinct terminal phase and were able to plan for their demise.

(b) Patients with cardiac failure had a chronic disease that progressed slowly with acute episodes of deterioration, no clear terminal phase and often unexpected or abrupt demise.

(c) Patients with lung cancer appeared to have access to adequate written information and understood about their illness and prognosis.

(d) Patients with cardiac failure did not appear to have access to adequate written information or clearly understand their illness and prognosis.

(e) Living with lung cancer the prospect of death was a real and unrelenting threat while this was not apparent with the patients living with cardiac failure.

(f) Side effects from treatments often produced worse symptoms than the actual disease for patients with lung cancer. Treatments for cardiac failure generally improved symptoms.

(g) Cancer was perceived as all consuming and taking over the individual's life. Cardiac failure was not viewed as the dominant concern because of the presence of comorbidities.

THIRD ORDER INTERPRETATIONS

Patients with non-malignant diseases were not so likely to have access to the psychosocial support services available to patients with malignant diseases.

The concept of prioritisation of support.

(h) Patients with lung cancer appeared to have more contact with professionals and services than the patients with cardiac failure. Failure to access services was sometimes caused through misunderstanding of roles regarding agencies and professionals.

The concept of prioritisation of support.

Appendix 6 Ethic committee approval

25 July 2005

Miss S.....
Acting Committee Administrator
Barking and Havering Local Research Ethics Committee
Room 7, 2nd Floor, Beckett's House
2/14 Ilford Hill, Ilford
Essex, IG1 2QZ

Dear Sandra

Full title of study: **Living with Multiple Myeloma (MM): A study to explore patients' experiences and supportive care implications.**

REC reference number: **05/Q0602/55**

Many thanks for your letter dated 21 July 2005 informing me of the information and clarification required to enable the Committee to give an ethical opinion regarding the above mentioned study. I am enclosing the following documents for further review by the Committee:

a) The patient information sheet and the information sheet for member of family or friend have been rewritten and simplified reducing the technical jargon as advised by the Committee. All information sheets were corrected to indicate that the research was reviewed by the Barking and Havering LREC.

b) The GP Letter has been written and will be used to inform the patient's GP of the patient's participation. (Attached to Patient Participation Information Sheet).

c) Page 2 of the Patient Participation Information Sheet has been amended to include "With your permission the researcher will invite a family member or friend to participate in the study"

d) If a patient agrees to participate and their family member or friend declines the patient will still be included in the study.

Please do not hesitate to contact me if any further clarification is required.

Yours sincerely

Patricia J Smith
(Clinical Trials Coordinator)

COPY

Barking and Havering Local Research Ethics Committee
Room 7, 2nd Floor
Becketts House
2/14 Ilford Hill
Ilford
Essex
IG1 2QX

Telephone:
Facsimile:

7th August 2005

Mrs Patricia Jean Smith
Clinical Trials Coordinator
Barts and The London NHS Trust
St Bartholomew's Hospital,
Haematology Dept, 1st Floor, PathBlock
West Smithfield
EC1A 7BE

Dear Mrs Smith

Full title of study: **Living with Multiple Myeloma (MM): A study to explore patients' experiences and supportive care implications.**

REC reference number: **05/Q0602/55**

The Chair of the Barking & Havering Local Research Ethics Committee reviewed the additional documentation on the 3rd August 2005, and was able to approve the commencement of this study by Chair's Action. .

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering Letter		25 July 2005
Participant Information Sheet	2	22 July 2005
Participant Consent Form	2	22 July 2005
Response to Request for Further Information		(None Specified)
Information sheet for Family member or friend	2	22 July 2005

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0602/55	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project,

Yours sincerely

pp **Chair**

Email: janet.carter@redbridge-pct.nhs.uk

Enclosures:

Standard approval conditions

Site approval form (SF1)

SF1 list of approved sites

Appendix 7 Participant information sheet and consent

PATIENT PARTICIPANT INFORMATION SHEET

Study title

Living with Multiple Myeloma (MM) - A study to explore patients' experiences and supportive care implications.

Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for taking the time to read this.

What is the purpose of the study?

This study will explore the meaning of living with an uncommon form of bone marrow cancer called Multiple Myeloma. Patients who have MM may be treated by various specialists including doctors known as Haematologists who specialise in blood disorders, Orthopaedic surgeons who deal with bone problems, and Nephrologists who treat abnormalities of the kidney or bladder. There is at present no cure and common treatments consist of chemotherapy, steroid medications and high dose chemotherapy followed by stem cell transplant. Stem cells are primitive cells found in bone marrow and blood which are taken from the patient or a donor and reinfused at a later time to stimulate the production of new blood cells and allow the bone marrow to recover following the high dose chemotherapy. MM can be unpredictable and there may be numerous periods of unplanned hospital visits. The purpose of the study is to gain an insight and to increase awareness of the problems these patients encounter which will have major implications for the nursing care of patients with MM and future research and education.

Approximately 30 participants will be recruited from within the (named) NHS Trust. The objectives of the study are to explore the meaning of "Living with Multiple Myeloma" in terms of the impact on an individual's personal or family life, professional or working life, close family members or friends, and to try to understand what health care and supportive care patients feel they require. Examples of supportive care are psychological, social and spiritual support.

Why have I been chosen?

You are being asked to consider taking part in this study because you have Multiple Myeloma.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part

you will be given the information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part in this study I would like to interview you about your illness. This interview will be recorded and arranged at a time and place that is most convenient to you. The interview will be very informal and will give you time to tell me about your experiences and needs. You will be given the opportunity to tell me what it is like living with Multiple Myeloma in your own words. For example the first question might be "please tell me what it was like when you were diagnosed with Multiple Myeloma". This then allows you to tell your own story. With your permission the researcher will invite a family member or friend to participate in the study. Your GP will also be informed about the project and your participation should you decide to take part.

How long will I be involved?

It is anticipated that the interview will take approximately 60-90 minutes. You may be contacted again for clarification of meaning to avoid misinterpreting any of your comments which have been transcribed from your recording.

What are the possible benefits of taking part in the study?

The information that we get from this study may help us to manage future patients with Multiple Myeloma better.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it. Your name will not appear on the transcript and you will remain completely anonymous. For the duration of the study only your initials and a number will be assigned to your interview so the researcher can identify you. For the writing of the final report only the number will remain so it will not be possible for any party reading the report (thesis) to identify you. Any information you give will be treated with complete confidentiality at all times. Your recording will be stored on the researcher's computer and this will be erased at the conclusion of the study.

What will happen to the results of the study?

Following completion of the research study the results will be widely distributed to all participants, patients, families, and NHS Trust personnel via written summaries, pamphlets, teaching materials, guidelines and care pathways. Results will also be
circulated to myeloma associations and healthcare professionals via websites, journal publication, and conference presentations.

Who is organising and funding the research?

The research is being organised by myself, a full time PhD university student who is also a Registered General Nurse, sponsored by the City University and

funded by the (named) NHS Trust, and the (named) Charitable Foundation.

Who has reviewed this study?
This study has been reviewed by the Barking and Havering Local Research Ethics Committee.

Contact for further information

Pat Smith

University:
Mobile:
Home:

E mail address:

Thank you for participating in this research study!

Version 2. Revised 22 July 2005.

Study Number:

CONSENT FORM

Title of Project: Living with Multiple Myeloma (MM): A study to explore patient's experiences and supportive care implications.

Name of Researcher: Patricia J Smith

Please initial box

1. I confirm that I have read and understand the information sheet dated 22 July 2005, version 2, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from City University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to my GP being informed of my participation in the study. ☐

5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature

Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

Appendix 8 Letter to patient (example)

02 March 2006

Dear Jack and Jill

Re study "Living with multiple myeloma (mm): A study to explore patients' experiences and supportive care implications

It was nice to see you recently Jack and glad you have almost completed this lot of treatment. I expect you are too! I hope you are not feeling too bad or too tired out. I am sending you a couple of information sheets one for you both if you would like to consider taking part. It is of course not something that you have to do but I would just ask you to think about it and let me know. Below is a list of items from my interview guide but I am interested in the issues that are most important to you as a family:

- Life before
- At the time of diagnosis
- Impact on personal or family life
- Impact on professional or working life
- Healthcare system
- Supportive care

I can come to you if that is o.k. or if you would prefer to see me at the hospital that is not a problem and I can see you any day (including weekends) whatever is convenient for you. My office number is above just at the School of Nursing around the corner close to the hospital. My mobile number is……and my home number is…. It would be lovely to see you again. I must say I do miss the clinical work much more than I had anticipated but at the same time I appreciate how lucky I am to do my own study, be a student full time, and still receive my full salary! It's great that I have my job to come back to when I have finished the project.

Best wishes to you and your family

Pat Smith

Enc.

Appendix 9 Integrated conceptual hypotheses

"Classic grounded theory is simply a set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area" Glaser and Holton (2004:2)

The research findings are summarised within a framework of integrated conceptual hypotheses contributing towards understanding the nature and impact of the disease and direction for further research.

Integrated conceptual hypotheses:

- Diagnosing multiple myeloma is difficult because of its rarity and non-specific onset. Routine blood and urine tests do not detect monoclonal proteins associated with the disease therefore specialised tests are required.

- Delay in diagnosis ultimately leads to delay in treatment and potentially impacts on prognosis. Where there are bone lesions, the probability of pathological fractures occurring is relatively high especially in an area of bone weakened by the presence of pre-existing disease (Schey and Pallister 2004). The probability is likely to be higher in undetected pre-existing bone disease. Bone pain is likely to intensify and extend to other areas. This will ultimately have a significant impact on quality of life and may mean exclusion from aggressive treatment such as high dose therapy (stem cell transplantation) restricting options.

- The shock of the cancer diagnosis (Thomas and Retsas, 1999; Maliski et al, 2002) and the emotional trauma that this significant disclosure evokes (Davis, 2002; Persson and Hallberg, 2004) is likely to have an impact on concentration levels and decision-making capabilities of the individuals concerned.

- The shock of a cancer diagnosis such as multiple myeloma is considered potentially further exacerbated because of its rarity, incurability and progressive nature.

- Decision-making capabilities are probably further weakened as a result of feeling overwhelmed with the vast quantity of information available concerning treatment options particularly when newly diagnosed.

- *Contention* in communication occurs through lack of understanding the medical jargon used (diverse discourse), the speed at which the information is delivered and the volume of information given.

- If the speed at which the information given is accelerated and the terminology used by healthcare professionals is 'foreign' or unfamiliar to individual recipients, levels of shock, bewilderment and psychological trauma are likely to be increased.

- Common colloquial language applied by healthcare professionals when communicating and discussing medical issues associated with a complex cancer may enhance understanding and lessen the degree of confusion or bewilderment.

- Living with multiple myeloma is synonymous with living with uncertainty. Uncertainty is likely to be more prolonged and intensified when compared to other diseases. Uncertainty in multiple myeloma is closely linked to the unpredictable nature of the disease, repetition of relapse and an unforeseeable future. Uncertainty is also associated with 'living on the edge', fear of refractory disease and fear of disability with advancing bone disease.

- Serious adverse events associated with treatment such as peripheral neuropathy may be prolonged or irreversible (Richardson et al 2006) and can have a monumental impact on the quality of life and daily activities of living.

- Individuals with sexual problems associated with their treatment or cancer are more likely to struggle on their own than seek counselling or advice from a healthcare professional as this is a difficult topic for people to discuss.

- Disruption to family life appears more intense for those with children still living at home.

- Parents knowledgeable and aware of the consequences of myeloma are more likely to be able to communicate with their children more effectively so that they can understand what is going on around them and prepare them for significant life changes (Scott et al 2003).

- Family members appear more supportive when 'visible signs' are apparent. Patients' 'visible signs' are often associated with side effects from medication and not from the disease. When individuals appear to look normal and healthy this is generally perceived as 'normal and healthy'.

- Disruption to working life can involve significant periods of absenteeism caused through hospital appointments and treatment regimes. The individual is more likely to maintain employment if the job is non-manual

(white collar) and employer/working colleagues provide continued support and understanding.

- *Contention* in accessing support services appears to be experienced by participants as a direct result of their supportive care needs not being adequately met or recognised.

Appendix 10 Original interview schedule

PATIENT INTERVIEW SCHEDULE GUIDE

Pre-interview phase
Follows initial contact - time taken to establish rapport and gaining trust
Explanations concerning aims of study
Explanations concerning participants involvement
Reassurances given regarding confidentiality and anonymity.
Explanations regarding both verbal and written consent.
Obtaining verbal and written consent from participant
Completing participant record and demographic sheet
Recording name, address, contact number in private and confidential record book.

Interview phase
Inform participant that the recorder has been switched on
The following open-ended question will be asked :

"What's it like living with multiple myeloma?"

"What's it like living with someone who has multiple myeloma?"

Further subsequent neutral or nondirective probes as suggested by Polit and Hungler, (1991) p 291 may be used where necessary :

- Is there anything else?
- Go on
- Are there any other reasons?
- How do you mean?
- Could you tell me more about that?
- Why do you feel that way?
- Would you tell me what you have in mind?
- Could you please explain that?
- Could you give me an example?

Concluding interview
The interview will continue until the participant shows signs of tiring or has exhausted the flow of conversation. It is anticipated that the interview will last for approximately 60-90 minutes.
Examples of questions for participants who found it difficult to talk without questions:

(1) Please tell me what it was like when you were first diagnosed
(2) What impact has Multiple Myeloma had on your personal life or family life?
(3) What impact has this had on your professional or working life?
(4) What difference does it make to your life?
(5) Describe how you view yourself and your illness.
(6) Describe how others view you and your illness.
(7) Describe the issues that are most important to you regarding the health care system
(8) Describe the issues that are most important to you regarding the supportive care system (explanation of what supportive care means giving examples).

Appendix 11 Topic guide

Topic Guide

Life before - Redefining life comparing with how it was before and reflecting on the consequences called perceptions of normality (Carter, H Macleod, R Brander, P and McPherson, K 2004)

At time of diagnosis - "Like a bolt out of the blue" and the feeling of life being turned upside down" (Persson, L and Hallberg, IR 2004). "It was too much to cope with and I felt in physical pain with the shock and trauma of this devastating news" (Davis, K 2002). Choosing not to tell the family and carrying on as normal – "I apparently have something funny with my blood and I need to take tablets for it" (Lewando, S 2003). Disassociation and denial – "when I got my diagnosis I felt as though it didn't concern me" (Thome, B Dykes, AK Gunnars, B and Hallberg, IR 2003).

Impact on personal/family life - Becoming the caregiver and the process of caring seen as a duty and not a burden. Hoping for a miracle cure and seeking alternative medicine. (Mok, E Chan, F Chan, V and Yeung, E 2003). "You start to think and worry about how the family is going to cope – who is going to do this and who is going to do that"? (McRobert 2004). "While reassuring my mum that things would be o.k. I was having recurring dreams about her funeral" (Davis 2002).

Impact on professional/working life - "I had been averaging five and a half to six hours of work per day, five days a week. This has recently become too demanding so I have reduced it by 1-1.5 hours per day" (Duffy, J 2002). "I wanted to be a normal person, not a cancer patient. I was forced to give in to my illness – to give up work and tell people I was ill" (Nason, G 2004).

Healthcare system - Encounters with healthcare professionals – they felt they were being listened to and their autonomy was respected while others felt neglected and pushed aside. Adopting a passive role and showing no interest in illness. Or a proactive role and being in control (Thome, B Dykes, AK Gunnars, B and Hallberg, IR 2003). Letting go and handing over the care to the healthcare professional (Mok, E Chan, F Chan, V and Yeung, E 2003).

Supportive care. - Receiving help and support from family members and friends. Not receiving any help and support from family members and not wanting to bother them by requesting help (Mok, E Chan, F Chan, V and Yeung, E 2003). "Family and close friends are almost always very supportive, but are often the reason I feel under stress – will I upset him/her if I tell them how I actually feel"? (Nason, G. 2003).

Appendix 12 Specific questions (analysis driven)

How long had you been unwell for before you were diagnosed?

Are you able to work?

Have you had any problems accessing support services?

Can you talk to me about the myeloma – what it is, how is it affecting your body, how is it affecting you as a person?

Are there any particular difficulties in your life – or what are the challenges of daily living?

Can you talk to me about the experience of undergoing chemotherapy or other treatment? Stem cell transplant?

Do you feel you are well informed and able to make decisions about treatment options?

Can you talk to me about the experience of relapse?

Can you talk to me about the experience of remission (knowing that the disease will return at some point?)

What's it like being monitored?

How do you cope?

What sort of support network do you have around you?

What do you worry about, what are your main concerns?

Is there anything that has been a struggle for you?

Can you describe changes as your illness evolves and the best ways of meeting your needs at different points in time?

If I was setting up a service for myeloma patients what would you like to see in that service if you were at home alone?

Is there anything you would like to talk about concerning your illness?

Appendix 13 Demographic data

PATIENT SAMPLE CHARACTERISTICS

Participant	Gender	Age	Ethnicity	Location	Occupation	Diagnosis	Type of myeloma	Family status
1	male	61-70	1	Essex	Retired engineer	03/12/2003	IgG Kappa	Married with 2 adult children
3	female	61-70	1	Essex	Retired printing	00/08/1987	IgG Lambda	Married with 2 adult children
7	male	61-70	1	Essex	Retired Office	00/03/2002	IgG Lambda	Married with 3 adult children
9	female	30-40	1	London	Architect	01/10/2004	IgG Lambda	Married with 3 year old child
11	male	51-60	1	Essex	Administrator	17/02/2001	IgG Kappa	Married with 3 adult children
14	male	41-50	1	London	Research market	00/09/2002	Lambda light chain	Married with 4 year old child
17	male	61-70	1	Essex	Ret' BT engineer	00/01/1997	IgG Kappa	Widowed with 2 adult children
18	female	61-70	1	Essex	Ret' Lecturer	02/04/2004	IgA Kappa	Spinster
19	male	61-70	3	Essex	Retired IT Bank	31/07/2002	IgG Kappa	Divorcee with 3 adult children
23	male	41-50	1	Essex	IT Architect Bank	00/08/2003	IgG Kappa	Married with 2 young children 3, 7
24	female	51-60	12	London	Ret'Cleaning Sup'	00/03/2006	IgA Kappa	Widowed with 3 adult children
25	male	61-70	13	London	Ret'Mechanic	00/00/1993	IgG Kappa	Married with 2 adult children
27	male	41-50	1	Essex	Electrician	00/12/1997	IgG Lambda	Married with no children
29	male	41-50	12	London	Ambulance driver	00/02/2006	IgG Kappa	Lives with partner (four children)
30	male	51-60	12	London	Teacher	00/05/2007	IgG Kappa	Lives with daughter
33	female	71-80	12	London	Retired secretary	00/00/2001	IgG Kappa	Lives with husband and 2 adult ch'
40	male	51-60	12	Essex	Retired plasterer	00/00/1993	IgG Kappa	Lives with wife and adult child'

Appendix 13

HEALTHCARE PROFESSIONAL SAMPLE CHARACTERISTICS

Participant	Gender	Age	Ethnicity	Professional status.	Service length	Specialised service
5	female	31-40	3	Transplant coordinator	15	9
6	female	31-40	13	Clinical trials nurse	7	4
20	male	31-40	11	GP	11	8
21	male	20-30	1	GP	5	18 mths
22	female	41-50	1	Myeloma CNS	23	10
26	male	31-40	6	GP	13	7
31	female	41-50	1	Palliative CNS	23	14
32	female	51-60	1	Palliative CNS	34	20
36	female	31-40	1	Haem'onc CNS	17	13
37	female	31-40	1	Myeloma CNS	16	12
38	female	41-50	1	Myeloma CNS	23	18
39	female	41-50	1	Myeloma CNS	21	14

Appendix 14 The emerging theory of *Contention* in multiple myeloma

Defining Contention

The theory of *Contention* is a raw substantive and descriptive theory, which has emerged through human struggle and adversity. A definition of *Contention* in multiple myeloma developed from the concept analysis (5.3.7) relates to experiences involving struggle, battle, disruption and disharmony. It is a multidimensional concept encompassing sociological, psychological and physiological manifestations. These four concepts are closely related but do not necessarily happen simultaneously or in any specific order. However, they are all present at some stage as a result of the concept *Contention* appearing. For example, there is 'feeling uneasy' (disharmony) at the pre-diagnosis stage. By the time a person attends the Haematologist in the Oncology Department many patients begin to realize that the illness is serious although they are waiting for the results of investigations to confirm the diagnosis and for the consultant to explain what the diagnosis means. Disharmony comes and goes and is therefore referred to as alternating much like osmosis or diffusion in relation to a cell. It returns when changes occur and the disease is slowly progressing (relapse). Following this there is struggle (difficulty) in coming to terms with the diagnosis, the treatment, complex terminology, hospital environment, and feeling generally overwhelmed with vast amounts of information. Battle (forcefulness) commences when the individual is able to see things in a more positive light and starts fighting the disease by taking medication, making necessary adjustments, learning, gaining knowledge and making informed decisions. There is major disruption (upheaval) to life style due to the presence of disease which has sociological, psychological, and physiological implications. The 'breadwinner' for example who is no longer able to work and support his wife and family results in a form of 'employment contention' causing monumental upheaval, emotional conflict and frustration.

Person

Person relates to patients, family and healthcare professionals. All participate in the provision of health and supportive care services. Person relates to role and identity such as being a parent, a spouse, a journalist or teacher. The individual person is considered in terms of size, age, gender, culture, ethnicity, outer appearance, inner character or behaviour, and role in society. The person is a unique and dynamic individual whose culture and life patterns have been influenced through family values, religion, education, society and surrounding environment. The person has cognitive thoughts, intelligence, memories, experiences, knowledge, various talents, capabilities and expertise.

Human beings have the power of resourcefulness and resilience when managing difficult and challenging situations. Disruption of normal existence through illness will have various consequences for individuals. The way in which the person responds and adapts to the disruption and the illness is determined through physical, emotional, cultural, spiritual and socio-economic ramifications. The person is a sociable human being and part of a family. Illness affects the family and not just the individual. Incurable and chronic disease has a

monumental impact on working and family life. Individuals are aware of their surroundings and sensitive to change or a threatening environment. The individual is growing and developing constantly within the environment. The person and the environment are closely associated but each is separate and interchangeable for example airborne transmission of disease,

Environment

The immediate environment consists of the hospital, community, work place, home and includes people, pets and general surroundings. The hospital is viewed in terms of an inpatient ward and clinical outpatient settings. Hospitals are located locally or further distance away (centres of excellence). Environment also relates to atmosphere and situations. For instance home may be perceived as a safer environment following hospitalisation in light of recent reports regarding outbreaks of clostridium difficile infections in hospitals (Carvel 2008). Experiences associated with medication can result in a different perception of surroundings and environmental imagery through hallucinations unique to the individual causing psychological disruption and disharmony (*Contention*).

Environments are constantly changing and one of the most crucial responsibilities of the family member (carer) or healthcare professional is to maintain safe and healthy surroundings for the sick or disabled person. Many people living with multiple myeloma appear acutely aware of their changing environments and take precautions to avoid crowded places so that they have minimal contact with others who may transmit harmful bacteria. They are constantly susceptible to infection because of their immuno-deficiency. *Contention* sometimes exists when situations are out of control and individuals are struggling to travel home by train during the rush hour or other public transport, for example having spent a long day on the chemotherapy day care unit receiving treatment.

Health

Maintaining optimal health is synonymous with promoting and maintaining a good quality of life. Health in the context of living with a symptomatic myeloma cannot be considered in terms of "*a state of complete physical, mental, and social well-being and not merely the absence of disease, or infirmity*" as broadly defined by the World Health Organisation (www.who.int 2003). The physical, psychological and social well-being of the whole family need to be taken into account. There are substantial variations along the illness trajectory in myeloma; optimizing health is challenging and maintaining a good quality of life is seriously threatened depending on the severity of bone disease and disability.

Treatment in multiple myeloma aims to stabilize the disease, prolong life and where possible promote and sustain a good quality of life. Health is viewed by many as a "roller coaster" ride with periods of "ups and downs" that is, being in a state of wellness with relative normality (stable disease), or relapsing and recommencing another line of chemotherapy. Maintaining health and a good quality of life while on treatment is problematic because of the toxicities associated with the chemotherapy agents. There exists a physical and emotional *Contention* that is associated with the impact of the disease and the impact of the treatment of the disease. Numerous prophylactic medications are

taken throughout the entire duration of treatment, some of which may be ineffective. The duration of treatment often continues for several months at a time. Stable disease may last for several months or years but is unlikely to extend beyond several years. Depending on the type of treatment, how the individual responds and the stage of disease, the median progression-free survival ranges between 3-54 months (Kyle and Rajkumar 2008). Between treatment periods when the disease is stabilized the psychological well-being of the individual is significantly affected. Individuals and their families are living 'on the edge'. They know that the disease will progress but they do not know how long it will be before the next relapse and this creates emotional discord and a feeling of 'ill at ease' or disharmony which is constantly present in their lives.

Nursing

Nursing has moved beyond the realms of vocation, commitment, duty and caring. The discipline has evolved into a science and technology of multiple specialist units and areas of expertise. Nursing is a culture and a skilful art that consists of a community or society of persons providing care within the environment. Modern nursing has become a global network of people communicating, interacting and collaborating through links with the Internet and attending conferences. The individual nurse or person who is trained in the profession of providing nursing care aims to be knowledgeable, compassionate and competent. Nursing is a technology of highly skilled professionals involved in the arts and crafts of nursing, teaching and educating, researching and ongoing professional development. Nursing strives for creativity, innovation and change in order to enhance the provision of nursing service and improve the quality of nursing care. Nursing is reparative and restorative. The ultimate goal is to provide the physical, emotional, spiritual and social support during illness and disability. The personal characteristics of the nurse caring for the disabled or unwell person are a fundamental component of nursing. The individuals receiving nursing care require a professional who is compassionate and trustworthy. A positive connection or engagement during interactions is essential in order to communicate effectively. Nursing requires effective communication and interpersonal skills in order to (a) establish a rapport, (b) work towards establishing a trustworthy partnership and (c) recognise and meet the needs of the individuals requiring assistance. Nursing is a process of bonding, nurturing and sharing during times of human struggle and disharmony (*Contention*). Furthermore there is the commitment of providing information and educating the disabled person so that the responsibility of care is shared. The objective of nursing is directed towards empowering the unwell or disabled individual when possible to regain control and independence; reduce the risk of complications during illness; assist in the recovery and rehabilitation of the unwell person; maintain the dignity, comfort and quality of existence for the dying person; inform and educate those undertaking the responsibility of caring; and educate the well individual and family in order to maintain fitness, well being and supportive care.

Shirley (F 002)
Struggle: "This struggle was the slow realisation that Bert would probably die within the next five years. I had to come to terms that we were offered a place on a clinical trial using a new drug called velcade. We were quickly prepared; lots of tests and x-rays, blood tests and ultrasounds and an MRI scan. This was all to commence in two weeks approximately, followed by a complicated regime of medication. How did we do this? Travel from home? Live in London? A hotel? Endless struggle! Daily treatment? Weekly treatment? I could barely cope at this stage, I can tell you. But we were so pleased to be offered this trial. So happy and very relieved and anxious to get going.
Battle: *We both had to be assertive and confident to ask the many queries re' how to cope with everyday traumas. Bert was determined from day one that he would beat multiple myeloma. He was constantly asking and questioning his progress. Fatigue was a big problem but this did not stop him. He always approached every situation from an engineering perspective. It is an up and down situation, forward and back, but never giving up. My support never wavered. If I became negative I could never have coped. During the 10 months of remission the battle eased, we relaxed a lot, we laughed, went on holiday even. The family support continued strongly especially our daughter* (a nurse) *who kept us up to speed with lots of good advice.*

Disruption: *The disruption was massive, the biggest in our forty years of marriage. There was the total change in daily life and leisure by comparisons/trends. I kept my own daily diary of events. It kept me sane and it reminded me of my own career* (nursing). *It created my own sense of homeostasis. Bert also found it helped him to be involved in his care and management. He interfered but once we had returned to our local hospital for treatment etc he relaxed and found life less disruptive.*

Disharmony: *He was moody. No doubt this was due to the effect of the diagnosis and the drug regime and the toxicity. He fought hard but he became irritable at times and physically fatigued. There was disharmony because we tried too hard to carry on as if there was nothing wrong. Slowly we slowed down and had to accept that the intervention of multiple myeloma was inevitable. I felt on edge at times and we were very jealous of close friends who were not plagued by illness. The effect of this caused us to become irritable with each other. We dealt with this with chats and hugs; we had such a strong relationship. Perhaps we should have asked for help, but we did not, we coped. There was disharmony with our son who had difficulty with the acceptance of his father's illness. He said we should be more positive! I now find 18 months later* (after Bert's death) *he is still terribly upset and grieves to date. He is improving and relating slowly with the rest of the family. Our daughter is as supportive as she has always been".*

Sally (P 018)
Communicating bad news in a good way or in a bad way

"So far my experience has been good. My GP handled the task of telling me he suspected myeloma in a very thoughtful and sensitive way, even though it was me who actually said the words 'I think you are trying to tell me that I have cancer.' I was of course stunned, numb and completely unable to think beyond being diagnosed with a potentially life-threatening illness and that I was going to die. Nothing can prepare or save the patient from having to experience the awful shock that diagnosis brings however well or badly it has been conveyed. However, my GP's swift referral meant that within 2 days I was contacted by phone with my hospital appointment and within a week I was seen by the consultant. I found this really reassuring and, along with on-line research on myeloma by the family, it saved the agony of going through the not-knowing and not-doing phase which adds to the already high levels of distress".

Using complex terminology

"I have found that clinicians will often use terminology that I don't always understand and I have to ask them to 'use English'. I get a better understanding when I talk to professionals from outside of the hospital setting ie Myeloma UK, hospice doctors and nurses etc. I do feel that I get the time I need with my clinicians but I constantly come away from an appointment not entirely sure what has been said because I am anxious and they use the language they know. This is where it helps to have someone else accompany you".

Living with uncertainty

"This is one of the biggest issues for me – the not knowing what is going to happen. Because myeloma is such a complex disease it makes life very uncertain. The need to live for the present is a way of coping but the nagging uncertainty of living with myeloma is never far behind and for me life is like a roller-coaster, the highs and the lows. At times it becomes very difficult to live with and I become prone to mood-swings".

Perceptions of the illness (others' reactions towards you and your illness)

"I don't hide my myeloma as I have long ago accepted that it is now part of me and we come as a package. However, I am still a person in my own right with or without myeloma and I try to present myself in that way. I have had no awkward situations with other people but I am constantly amused by people feeling the need to tell me how well I look even when I often feel unwell. I think it is their way of coping with the discomfort they feel when confronted with an illness that they dread for themselves".

Novice to expert patient

"Having had no knowledge of myeloma before my diagnosis it was important that I learnt about it but I found it almost impossible in the beginning as I really did not want to know anything that had to do with myeloma. I was just too terrified to know what was going to happen to me. I was given booklets/leaflets from the hospital but could only read them some months after diagnosis and when I started treatment. It was then that I began to acquire some knowledge. My inclinication to want to know more about myeloma only comes at each stage of the illness and treatment. I think I will only become an 'expert' when I truly am dying. My expertise in myeloma only evolves when I have to face every

new stage and although I am an active member of Myeloma UK I struggle with the discussion boards because of other peoples' experiences which I know won't necessarily apply to me but I am still afraid to face".

Disrupted life
"I suppose any illness will cause a disruption to life so I don't think that myeloma disrupts more than any other really".

Physical impact of disease
"Currently my illness does not restrict me from leading a near-normal life when I am off-treatment other than fatigue which comes from my low blood counts after the stem cell transplant. This requires me to have weekly blood tests and blood transfusions when needed. I did have to give up work but as I was at retirement age and once I had come to terms with it, I realised that I would not have had the energy to continue working".

Emotional impact of treatment
"It is emotionally exhausting because the physical impact leaves me unable to lead anything like a normal life and I often become low or even depressed by it. The fear of wondering whether or not it will work, the physical side-effects and not being able to function properly all play a big part in emotional distress. Also, the drug Dexamethasone plays havoc with my mental health to the point where I can only tolerate low levels of the drug. This obviously has an effect on my treatment".

Physical impact of treatment
"This is a big issue and often requires a lot of tinkering with drugs by the clinicians before getting medication right to relieve some of side-effects (see comments on Dexamethasone above). The biggest impact is the chronic fatigue which seriously affects mobility, which in turn affects my domestic and social life".

Social/economical impact of disease
"My social life is heavily affected when I am receiving treatment but when off-treatment it is less so. However, the need for regular hospital check-ups, blood tests and transfusions severely restricts how far and long I can be away from home which means no holidays abroad and limits stays in the UK. Financially, as I am now retired I have a small corporate pension, the state pension and DLA, which allows me to make ends meet. I did not anticipate giving up work at 60 if I had been well, so it has affected me economically in restricting my ability to carry on working".

Support needs
"I attend the Day Care Unit at my local hospice where they support me through my treatment and I also have counselling and complementary therapies at the (named centre) 'Cancer Centre. Whilst I have been caring for myself since first diagnosed 4 years ago, I sometimes have to be cared for during or after treatment and I do worry about how I will cope when my disease becomes more disabling".

Sexuality
"I can only comment that chemotherapy drugs cause a very decreased libido and that affects an individual's sex life".

Invisible struggle
"I think my biggest struggle is dealing with my own feelings and emotions on my own and without causing anxiety to family and friends. This is where I find my counselling so invaluable".

Impact of policy/legislation
"This for me and I am sure other patients is a really big issue. So far I have not been denied the drugs recommended because of being on clinical trials. However, I think it will only be a matter of time before I am affected by government policies on cancer drugs and NICE's appraisal system which works on cost-effectiveness rather than clinical need. This can be hugely stressful for patients and families alike. There should not have to be this stress at a time when living with myeloma causes its own stress. I can only hope that Lord Darzi's recent recommendations for the next 10 years of the NHS eliminates this and makes these drugs available on an equal basis".

Decision-making
The very nature of myeloma and its unknown prognosis makes it very difficult – if not almost impossible – to make any decisions in the short and long term. Treatment can make me feel so ill that I am quite incapable of making a rational decision. Other times when not on treatment my rational thinking is better but the ever present threat of relapse and more treatment means that decisions other than normal day to day decisions are difficult to make. I think that is the best way that I can describe it.

Frank (P 007)
Struggle: "*Going back to the beginning of it, I wasn't obviously even aware that I had this myeloma and to me life was pretty good five and a half years ago, and there hadn't been any struggle from the time that I was told that I had this problem. I just went about my life in the normal sort of way, there was no struggle at that time. I reckoned I was pretty fit for my age in those days but the struggle was something that developed as the years went by, and I would say that really the last two years have been a bit of a struggle, from the point of view of physical deterioration and because of the physical deterioration, there was a concomitant frustration mentally that evolved from not being able to do the things I wanted to do. The pain began to assert itself in the joints and life was becoming pretty difficult and pretty miserable because of the impact of all the ongoing medication and all of the side effects produced by the medication. So yeah, struggle, the last two years have definitely been a struggle, as the condition has got worse, so the struggle has become more severe".*

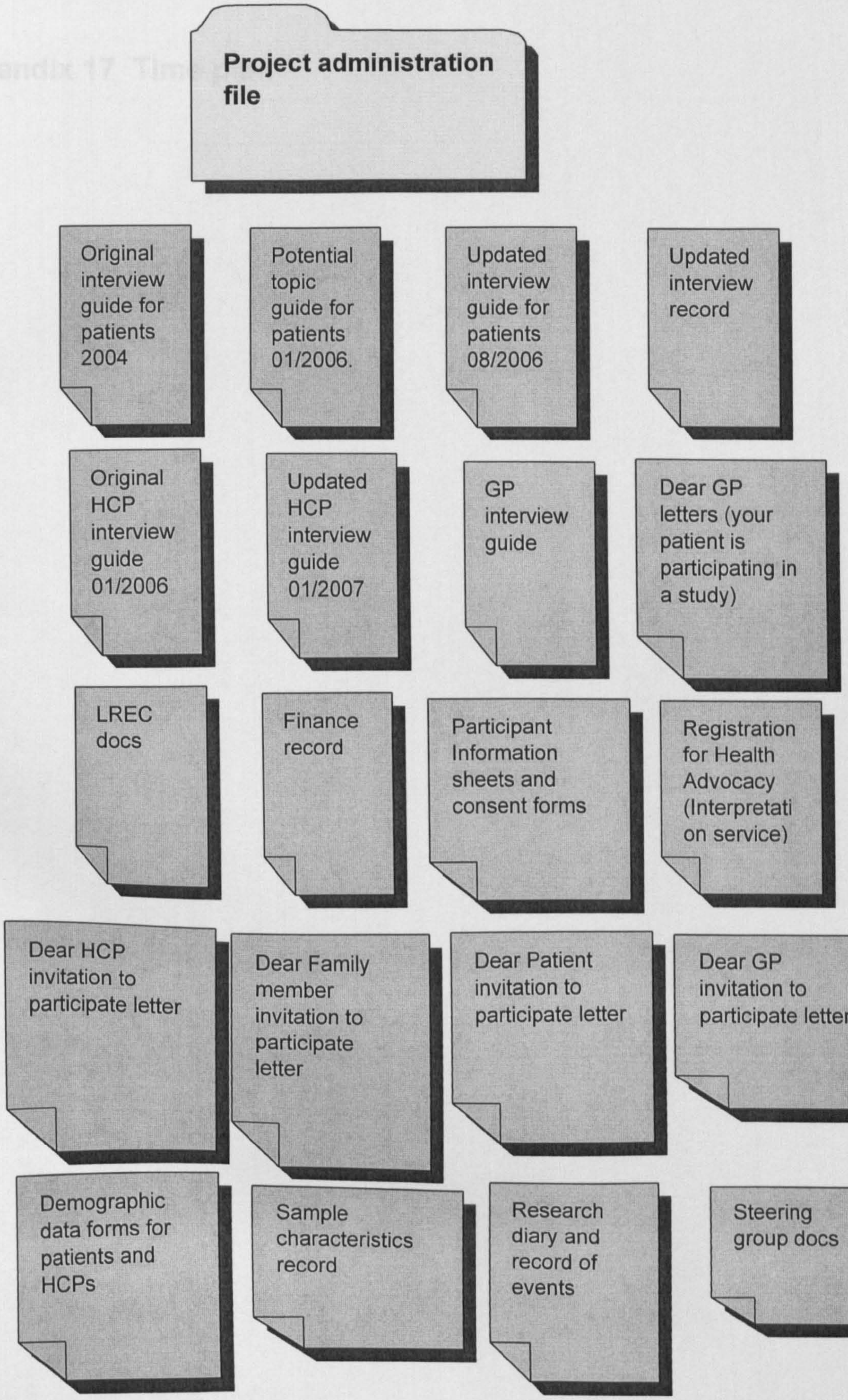
Battle: "*Oh yes, oh yes, it's a fight. It's an ongoing fight. I mean…you know, the fight is to, to sustain life it's as simple as that, that is the fight".*
Disruption: "*Well the disruption is that I no longer have the energy to get on and lead what I would say is a normal days activities. I am so much lacking in energy that there is a complete different way that I fill the day. I don't walk as*

much as I would like to, I don't cycle as much as I would like to, I can't play golf anymore, to me the condition is totally restricting my lifestyle, totally".

Disharmony: "*Lets open it up and encompass the whole of the family. Way back five and half years ago I got the whole family together and told them that I had multiple myeloma and it was a very tearful scene when, when they realised that this, this was an incurable form of cancer. I told them in such a manner as to be gentle with them because it's a, it's a terrible thing to have to tell the entire family that this is an incurable condition. There was a great deal of upset...a great deal of emotional, there were floods of tears, cuddling and all that. Now that was five and a half years ago. Now during the five and a half years there has never been any embarrassment with the family members. My own three, our own three children, the grandchildren, life has gone on pretty normal because I've never dumped my lot on them, they have their own lives to lead. They're getting on in the world, with their careers, with bringing up their children and to be honest, my condition has had no impact on their lives at all".*

Appendix 16 Project administration file

Appendix 16. Project administration file.



KEY: HCP = Healthcare Professionals; LREC = Local Research Ethics Committee

Appendix 17 Time plan

	Oct-05	Nov-05	Dec-05	Jan-06	Feb-06	Mar-06	Apr-06	May-06	Jun-06	Jul-06
Attending seminars										
Training for ref manager										
Training for qualitative software										
Literature searching										
Reading										
Updating review										
Main data collection										
Main data analysis										

	Aug-06	Sep-06	Oct-06	Nov-06	Dec-06	Jan-07	Feb-07	Mar-07	Apr-07	May-07
Continued data collection										
Continued data analysis										

	Jun-07	Jul-07	Aug-07	Sep-07	Oct-07	Nov-07	Dec-07	Jan-08	Feb-08	Mar-08
Continued data collection										
Continued data analysis										
Drafting thesis										

	Apr-08	May-08	Jun-08	Jul-08	Aug-08	Sep-08	Oct-08
Drafting/writing up of thesis							
Submission and Viva Voce							
Dissemination							

Appendix 17 Time Plan.

Appendix 18 Interview record

INTERVIEW RECORD

1	**P**		RIP	transcribed	field notes	**coded***		
2	**F**			transcribed	field notes	**coded***		
27	**P**	**Lost**	**found**	Mar-07	**field notes**	coded		
28	**F**	**Lost**	**found**	Mar-07	field notes	coded		
0	**P**		RIP	Incomplete	**field notes**	**Poor quality**		
3	**P**	29/01/2006	RIP	transcribed	field notes	**coded***		
4	**F**	29/01/2006		transcribed	field notes	**coded***		
1	**P**	01/02/2006		transcribed	field notes	coded	**follow up**	
2	**F**	01/02/2006		transcribed	field notes	coded	**follow up**	
5	**HCP**	16/02/2006		transcribed	field notes	coded		
6	**HCP**	09/03/2006		transcribed	field notes	coded		
7	**P**	10/03/2006	RIP	transcribed	field notes	coded	**Validation visit 12/10/2007**	**Frank died 30/01/2008**
8	**F**	10/03/2006		transcribed	field notes	coded		
9	**P**	14/03/2006	RIP	transcribed	field notes	**coded***		
10	**F**	14/03/2006		transcribed	field notes	**coded***		
11	**P**	27/03/2006		transcribed	field notes	coded		
12	**F**	27/03/2006		transcribed	field notes	coded		
13	**F**	11/04/2006		transcribed	field notes	**coded***		
14	**P**	14/04/2006		transcribed	field notes	**coded***		
15	**F**	14/04/2006		transcribed	field notes	**coded***		
16	**F**	19/04/2006		transcribed	field notes	coded		
17	**P**	29/06/2006	RIP	transcribed	field notes	**coded***		
18	**P**	10/07/2006		transcribed	field notes	coded		
19	**P**	07/08/2006	RIP	transcribed	field notes	**coded***		
20	**HCP**	18/01/2007		transcribed	field notes	coded		
21	**HCP**	18/01.2007		transcribed	field notes	coded		
22	**HCP**	23/01/2007		transcribed	field notes	**coded***		
23	**P**	24/01/2007		transcribed	field notes	coded		
24	**P**	20/02/2007		transcribed	field notes	coded		
25	**P**	26/02/2007		transcribed	field notes	coded		
26	**HCP**	28/03/2007		transcribed	field notes	coded		
27	**P**	28/06/2007		transcribed	field notes	coded	**follow up and validation**	
28	**F**	28/06/2007		transcribed	field notes	coded	**follow up and validation**	
29	**P**	19/07/2007		transcribed	field notes	coded		

30	**P**	02/08/2007	transcribed	field notes	**coded***
31	**HCP**	21/08/2007	transcribed	field notes	coded
32	**HCP**	23/08/2007	transcribed	field notes	coded
33	**P**	01/10/2007	transcribed	field notes	coded
34	**F**	01/10/2007	transcribed	field notes	coded
35	**F**	01/10/2007	transcribed	field notes	coded
36	**HCP**	02/10/2007	transcribed	field notes	coded
37	**HCP**	05/10/2007	transcribed	field notes	coded
38	**HCP**	11/10/2007	transcribed	field notes	coded
39	**HCP**	11/10/2007	transcribed	field notes	coded
40	**P**	13/11/2007	transcribed	field notes	coded

Key: coded* = seen by Mary (member checking)
P=Patient, F=Family member, HCP=Healthcare Professional

Appendix 19 Family self-assessment and referral plan

Page (1) **Introduction.**
Patients and their families may need help at specific points in time during illness. They may not be aware of their supportive care needs especially during difficult periods when they are unable to think or concentrate clearly. For example newly diagnosed patients and their families need time to come to terms with the news of a cancer diagnosis. They may, therefore, need someone to explain about the cancer at another time when they feel more prepared to take on board this information. The information in this leaflet is based on research involving patients, families and healthcare professionals to help others identify their needs. The contact details inside will give families access to a healthcare professional who can advise or make a referral to the appropriate person who can help.

Page (2) **Helping you to identify your supportive care needs.**
When you are diagnosed with a blood or a bone marrow cancer like multiple myeloma you and your family will require time to get over the initial shock. At this distressing time you may not be aware of the kind of help you may require at any particular moment in time. This leaflet has been designed to help you identify your supportive care needs such as practical help in the home, emotional support, or family counselling. It will also help you by providing contact details of the local Clinical Nurse Specialist and Macmillan Nurse who can advise you or refer you to the appropriate person.

When am I likely to need help?

Newly diagnosed
Starting treatment
Having a stem cell transplant
Times of relapse
Times of remission (being monitored)
Following hospitalisation
Times of uncertainty

Page (3) **What kind of help do I need?**
Is there someone I can speak to concerning:
Feeling depressed or anxious?
Helping me to explain my illness to the children?
Helping me to understand my illness?
Treatment options?
My current medication and side-effects?
Financial concerns?
Benefits and allowances?
Childcare?
Preparing meals?
A local support group?
Introduction to someone who has the same cancer as my own so I can talk things through?
Travel insurance?
Private health insurance?
Getting a wheelchair?
Modifications to my home for easy access?

Page (4) **Contact details**
Clinical Nurse Specialist
Name.....
Phone.....